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THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT OF 1990

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Mr. KENNEDY, from the Committee on Labor and Human Resources, submitted the following

REPORT

[To accompany S. 2753]

The Committee on Labor and Human Resources, to which was referred the bill (S. 2753) to revise and extend the Developmental Disabilities Assistance and Bill of Rights Act, and for other purposes, having considered the same, reports favorably thereon with an amendment and recommends that the bill (as amended) do pass.

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I. SUMMARY OF THE BILL

The Developmental Disabilities Assistance and Bill of Rights Act (the Act) has four components: the basic State grant program; the protection and advocacy systems; the university affiliated programs; and projects of national significance.

S. 2753, the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1990 (the bill), reaffirms the thrust of the basic State grant program and includes several amendments that clarify and strengthen the program. The findings section of the bill focuses on the capabilities, competencies, and preferences as well as the needs of persons with developmental disabilities and

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emphasizes the important role the family and members of the community can play in enhancing the lives of persons with developmental disabilities. The importance of providing interdisciplinary training and technical assistance to professionals, paraprofessionals, family members and individuals with developmental disabilities, and protecting their legal and human rights are cited as important for assuring the provision of necessary support services aimed at creating opportunities for maximum independence.

The bill maintains and further strengthens the independence of the State Planning Councils to carry out advocacy, policy analysis, system enhancement and other activities under the Basic State Grant Program which will have a positive impact on the greatest numbers of persons with developmental disabilities and their families. The bill provides that findings from the comprehensive review and analysis of services to people with developmental disabilities conducted by each State Planning Council, termed the "1990 Report", be used in future State planning activities to assure that comprehensive services are made available to the identified unserved and underserved populations. The bill also expands a Federal priority activity area, and maintains State flexibility in selecting priority areas in which to focus activities which respond to State differences.

The bill authorizes to be appropriated for the Basic State Grant Program $81,270,000 for fiscal year 1991, $85,335,000 for fiscal year 1992, $89,600,175 for fiscal year 1993, and $94,080,190 for fiscal year 1994.

The bill adds several clarifying provisions regarding the role of the Protection and Advocacy System in representing persons with developmental disabilities and engaging in systems advocacy, the independence of the Protection and Advocacy Systems, appointments to the Governing Board, the conditions under which Protection and Advocacy Systems have access to records, and the process for redesignation of the State agency which implements the System.

The bill authorizes to be appropriated for Protection and Advocacy Systems $27,000,000 for fiscal year 1991, $28,350,000 for fiscal year 1992, $29,770,000 for fiscal year 1993, and $31,258,500 for fiscal year 1994.

The bill retains the focus on the part of the legislation establishing university affiliated programs (UAPs) which are designed to assist in the provision of interdisciplinary training, the demonstration of exemplary services and technical assistance, and the dissemination of information which will increase and support the independence, productivity, and integration into the community of persons with developmental disabilities.

The bill permits universities to apply for funds to study the feasibility of establishing new UAPs and satellite centers and directs the Secretary of Health and Human Services to consider expanding the numbers of UAPs and centers into unserved States as the first priority. In addition, the bill continues core funding for existing UAPs and creates supplemental core funding for the purpose of training personnel to address the needs of persons with developmental disabilities in areas of emerging national significance. The bill provides for assuring the appropriateness and quality of such

training activities. The bill requires that UAP's create a consumer advisory committee.

Separate line items are established for core administrative funding and for core training grants. The bill authorizes to be appropriated for core administrative funding $11,400,000 for fiscal year 1991, $12,390,000 for fiscal year 1992, $13,430,000 for fiscal year 1993, and $13,429,000 for fiscal year 1994. For core training funding, the bill authorizes to be appropriated $7,000,000 for fiscal year 1991, $8,652,000 for fiscal year 1992, $10,386,000 for fiscal year 1993, and $12,050,000 for fiscal year 1994.

Finally, the bill authorizes the Secretary to make grants to, or enter into contracts with, agencies and nonprofit entities for projects of national significance relating to persons with developmental disabilities to educate policymakers, develop an ongoing data collection system, determine the feasibility and desirability of developing an information and referral system, pursuing interagency initiatives and other projects of sufficient size and scope which hold promise of expanding opportunities for persons with developmental disabilities. The bill authorizes to be appropriated $3,900,000 for fiscal year 1991, $4,095,525 for fiscal year 1992, $4,299,750 for fiscal year 1993, and $4,514,800 for fiscal year 1994.

II. Background and Need for the Legislation

THE 1970 AMENDMENTS

The Developmental Disabilities Services and Facilities Construction Amendments of 1970, P.L. 91-517, was the first congressional effort to address the needs of a group of persons with handicaps designated as developmentally disabled. P.L. 91-517 amended the Mental Retardation Facilities and Community Health Centers Construction Act of 1963. The 1970 amendments defined developmental disability to include persons with mental retardation, cerebral palsy, epilepsy, and other neurological conditions closely related to mental retardation which originate prior to age 18 and constitute a substantial handicap.

The 1970 amendments authorized State allotments for planning, services, and construction of facilities for persons with developmental disabilities. A State plan was required which was to designate a State planning and advisory council. One-third of the Council was to be comprised of consumers of service. The State plan was to describe the quality and extent of services and to show how funds were to be used to augment, rather than duplicate, services already available.

Grants to help support interdisciplinary training in institutions of higher education were authorized to help meet shortages of personnel to provide services to persons with developmental disabilities. This has become known as the university affiliated program.

A National Advisory Council on Services and Facilities for the Developmentally Disabled was also authorized.

THE 1975 AMENDMENTS

The Developmentally Disabled Assistance and Bill of Rights Act, P.L. 94-103, required that protection and advocacy programs be es-

tablished in each State as a condition to receive the State grant. The protection and advocacy systems were designed to protect and advocate for the rights of persons with developmental disabilities and to pursue legal, administrative, and other remedies to ensure the protection of rights for such persons.

The 1975 amendments added the "Rights of the Developmentally Disabled," which included congressional findings such as the right to appropriate treatment and services designed to maximize individual potential.

The Federal discretionary grant authority was added by the 1975 amendments. Grants were authorized for demonstration service projects, public information and for other activities designed to improve services for persons with developmental disabilities.

The definition of developmental disability was expanded to include autism and dyslexia, if such dyslexia resulted from one of the other disabilities included in the definition.

The 1975 Amendments defined university affiliated facility to mean a part of a college or university that has a demonstration service program and provides education and training, including interdisciplinary training to persons needed to render service to persons with developmental disabilities. Satellite centers were authorized to extend training and services to unserved areas.

The Amendments added a requirement that all persons served under authorized programs have in effect a written habilitation plan which states long-term habilitation goals, intermediate objectives, and a plan for service delivery.

THE 1978 AMENDMENTS

Title V of P.L. 95-602 amended the Act by authorizing a revised definition for the term developmental disability. Prior to the 1978 Amendments, the term was defined to include mental retardation, cerebral palsy, epilepsy, autism, and certain other neurological conditions. A major provision of the 1978 Amendments modified this definition by deleting all references to specific handicapping conditions and establishing a definition based on functional limitations.

The 1978 Amendments established four priority service areas and required that States choose not more than two priority service areas for expenditure of not less than $100,000 or 65 percent of the State grant funds, whichever was greater. The four priority service areas were: case management services, child development services, alternative community living arrangement services, and nonvocational social-developmental services.

The Amendments repealed authorization for the National Advisory Council on Services and Facilities for the Developmentally Disabled.

OMNIBUS BUDGER RECONCILATION ACT OF 1981

P.L. 97-35, the Omnibus Budget Reconciliation Act of 1981, provided authorization for the developmental disabilities programs for FY1983 and FY1984 and repealed a requirement for individual evaluations of persons served under this Act.

THE 1984 AMENDMENTS

The Developmental Disabilities Act of 1984, P.L. 98-527, added a statement of purpose to the Act which specified that programs authorized are to help assure that persons with developmental disabilities achieve their maximum potential through increased independence, productivity, and integration into the community.

The 1984 Amendments added employment-related activities as one of the priority service areas. Employment-related activities were specified as one of a State's priority service activities after FY1986 if the appropriation for the State grant program equals or exceeds $50.25 million in that year. The Amendments provided that States may choose up to three priority service areas beginning in FY1987. The Amendments deleted nonvocational social-developmental services as a priority service area, but retained authorization for these services on a nonpriority basis. Also, services to promote and coordinate activities to prevent developmental disabilities were authorized by the amendments.

The State Planning Council membership was required by the Amendments to include representatives of the State agencies that administer the Rehabilitation Act, the Education of the Handicapped Act, and Title XIX of the Social Security Act (Medicaid), as such title affects persons with developmental disabilities. Protection and advocacy systems, higher education training facilities, and each university affiliated facility (program) or satellite center in the State are to be represented on the Council.

The Amendments required that not more than 25 percent of the State grant funds be allocated to the administering agency for the provision of services by such agency.

Minimum allotments established for the Protection and Advocacy System by the Amendments provided that when appropriations reached $47 million, States were to receive a minimum allotment of $300,000 (compared to $250,000 prior to the amendments) and territories were to receive a minimum of $160,000 (compared to $100,000 prior to the amendments).

The Amendments prohibited States from redesignating the agency that administers the protection and advocacy system unless the State determines that good cause existed for the redesignation. States must give notice to persons with developmental disabilities or their representatives regarding any intention to redesignate. Information and referral services were authorized for protection and advocacy systems.

Protection and advocacy systems were given access to the records of persons with developmental disabilities living in residential facilities if there are complaints regarding the facility and if the individual does not have a legal guardian or the State is the legal guardian.

Minimum allotments established by the 1984 Amendments provided that when appropriations equalled or exceeded $11 million, States were to receive $150,000 (compared to $50,000 prior to the amendments), and territories were to receive a minimum of $80,000. (There was no statutory minimum for territories prior to the 1984 amendments.)

The 1984 Amendments provided that no new university affiliated facilities (programs) were to be funded after FY1985 unless a feasibility study had been conducted and the need for the facility documented. Applications for university affiliated facilities and satellite centers were required to provide assurances that the human rights of persons receiving services were protected according to section 100 of the Act, Rights of the Developmentally Disabled.

When appropriations reached $8.5 million, the minimum amount for a grant to a university affiliated facility was to be $17,000. (The previous grant minimum was $150,000.) The minimum grant to a satellite center, $75,000, was not changed by the 1984 amendments.

The 1984 Amendments specified that special projects are to expand and improve services to underserved groups of persons with developmental disabilities, including Native Americans and Native Hawaiians.

THE 1987 AMENDMENTS

The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 recognized and emphasized the capacity of the individual with developmental disabilities rather than limitations. Language used reflected the most up-to-date thinking on approaches for enabling persons with developmental disabilities to achieve thier maximum potential through increased indpendence, productivity, and integration into the community. The Amendments also recognized the central role that family and members of the community, including friends and neighbors, can play in enchancing the lives of persons with developmental disabilities.

The 1987 Amendments also clarified and strengthened the independence of the State Planning Councils to carry out their advocacy role under the Act and refocused the activities the Council funds to include policy analyses and other activities that were most likely to have a positive impact on the systems which affect the greatest numbers of persons with developmental disabilities. The bill also amended the State plan to require States to take a hard look at how they are meeting the needs of persons with developmental disabilities attributable to a physical impairment, a mental impairment, or a combination of physical and mental impairments. The bill also increased State flexibility in selecting priority areas in which to focus their efforts.

Minimum allotments to States were increased from $300,000 to $350,000 by the 1987 Amendments when the appropriations level exceeds $60,000,000. The Amendments authorize the Secretary to increase the minimum allotment administratively when the increase in the appropriations is greater than the Consumer Price Index.

The 1987 Amendments added several provisions designed to enhance the accountability of the protection and advocacy system by: ensuring particular attention to be paid to the needs of members of racial and ethnic minorities who are developmentally disabled; required the establishment of a grievance procedure; and providing the public with an opportunity to make public comment on the priorities established by the System.

The bill clarified that access to the records of a person with developmental disabilities applies to a person who resides or was abused or neglected while residing in a facility for persons with developmental disabilities. The Bill also clarified the authority of the protection and advocacy system to investigate incidences of abuse and neglect reported to the system if there is probable cause to believe that the incidents reported occurred. These changes are consistent with comparable authority set out in the Protection and Advocacy for Mentally Ill Individuals Act of 1986, P.L. 99-319.

Minimum state allotments to protection and advocacy systems were increased under the Amendments from $150,000 to $200,000.

The 1987 Amendments retain the current focus of the part of the legislation establishing university affiliated programs (UAPs), which are designed to assist in the provision of interdisciplinary training, the demonstration of exemplary services and technical assistance and the dissemination of information which will increase and support the independence, productivity, and integration into the community of persons with developmental disabilities.

Under the Amendments, universities were permitted to apply for funds to study the feasibility of establishing new UAPs and satellite centers and the Secretary of Health and Human Services was directed to consider expanding the number of UAPs and centers into unserved States. In addition, applicants were required to demonstrate the coordination between its activities and the activities conducted by the State under the State plan.

The Amendments created separate line items for core funding and for the funding of grants. Core funding appropriations were $9,400,000 for FY1988, $10,200,000 for FY1989, and $11,000,000 for FY1990. For grants to university affiliated programs, the Amendments authorized to be appropriated $4,500,000 in FY1988, $5,000,000 in FY1989, and $5,500,000 in FY1990.

Finally, the Amendments renamed the special projects part of the bill to read "projects of national significance." Authorization was given to the Secretary to make grants to, or enter into contracts with, agencies and nonprofit entities for projects of national significance relating to persons with developmental disabilities to educate policymakers, develop an ongoing data collections system, determine the feasibility and desirability of developing a nationwide information and referral system, pursue interagency initiatives and other projects of sufficient size and scope which hold promise of expanding opportunities for persons with developmental disabilities. Under this section, $3,650,000 was authorized to be appropriated for each of the fiscal years 1988-1990.

HEARINGS AND TESTIMONY

Witnesses

The Subcommittee on Disability Policy held hearings on Friday, March 30, 1990 to consider the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act.

The first panel consisted of Ms. Deborah L. McFadden, Commissioner, Administration on Developmental Disabilities. Ms. McFadden discussed the continuing importance of the Developmental Disabilities Program. She spoke of the need of flexible legislation

which will allow for emerging trends and the capacity to respond to the comprehensive report conducted pursuant to the 1987 Amendments to the Developmental Disabilities Assistance and Bill of Rights Act. Ms. McFadden emphasized the role of the Planning Councils as a "bridge builder" and advocates for system change. She spoke of the need for Protection and Advocacy Systems to address continuing as well as emerging issues. Further, she emphasized the importance of the training initiatives undertaken by the University Affiliated Programs as a result of the 1987 Amendments and spoke about their accomplishments. She told of the development and use of peer review as a means of ensuring quality of program. Finally, Ms. McFadden spoke of the continuing UAP expansion, and the success of the expansion efforts since the 1987 Amendments.

The second panel consisted of three individuals who have directly benefited from or have family members who have benefited from programs, activities, or services generated from the Act: Dr. Elizabeth Boggs, Dr. Charlie Lakin and Ms. Helen Coburn Roth.

Dr. Elizabeth Boggs, the parent of an adult man who has developmentally disabilities, testified on behalf of the Developmental Disabilities Taskforce for the Consortium for Citizens with Disabilities (CCD). The Task Force is comprised of more than 15 national disability organizations including advocates, parents, consumers, providers, and professional groups, who are most concerned with and involved in the developmental disabilities program.

Dr. Boggs was a founding member of the Association for Retarded Citizens, has served on the State Planning Council in New Jersey, and chaired the first National Advisory Council on Services and Facilities for the Developmental Disabled. She also served on the Task Force on University Affiliated Programs constituted by the Office of Human Development Services. Her testimony recounted the long history of CCD and their comprehensive work on behalf of citizens with developmental disabilities across a broad spectrum of programs and policies. Dr. Boggs made numerous recommendations, on behalf of CCD, to both fine tune and change existing statutory provisions designed to enable the Act to remain on the cutting edge of best practice in the field, and further enable achievement of goals of the Act—independence, productivity and integration of persons with developmental disabilities. She emphasized that these recommendations were made in the context of overall satisfaction with the current direction of the law and accomplishments of the four programs.

Dr. Charlie Lakin, of Minneapolis, Minnesota, has been the foster parent of a yound woman with developmental disabilities and is also the Director of Research and Information for the Minnesota University Affiliated Program. The young woman for whom Dr. Lakin served as a foster parent has now returned to her family, but is with Dr. Lakin and his wife on many weekends—as respite to the family. Dr. Lakin described the Developmental Disabilities Act as banner legislation for a national movement of inclusion of people with developmental disabilities in this country. He emphasized that consumers, families, providers, academics, state and federal program personnel and policymakers are involved with one another under the provisions of the Act. He made recommenda-

tions about new training areas that should be considered in the future and stressed the importance of the projects of national significance.

Mr. Helen Coburn Roth, from Logan, Utah, is the Director of a Northern Utah Independent Living Center. She contracted polio when she was 12, and went on to finish high school, a Bachelor of Arts and a Masters degree in psychology. She volunteers a great deal of time to health, community and consumer issues in Utah, and founded the Cache County Handicapped Action Council. Ms. Roth testified about how important assistive technology has been to her personally, pointing out that it meant liberation to her. She emphasized the integral and critical role assistive technology can play in the life of a person with a developmental disability and the importance of making assistive technology more readily available.

The third panel was composed of witnesses who were representatives for the three programs created by the Developmental Disabilities Act: Mr. Ken Campbell, Mr. Henry Brown, and Dr. Al Healy.

Mr. Ken Campbell, from Columbus, Ohio, spoke on behalf of the National Association of Developmental Disabilities Planning Councils (NADDC). He has been the Executive Director of the Ohio Developmental Disabilities Planning Council for three years, and is the President-elect of NADDC. Mr. Campbell stressed the important role the Councils play in moving public policy forward. He talked about the significant effort undertaken by the Councils in response to the comprehensive report mandated by the 1987 Amendments to the Developmental Disabilities Act and their importance as a basis for establishing future policy directions.

Mr. Henry Brown, from Greenville, South Carolina, is the parent of a young woman who is mentally retarded and mentally ill. He is also the Chairman of the Advisory Board for the Protection and Advocacy Agency in South Carolina and spoke on behalf of the National Association of Protection and Advocacy Systems (NAPAS). He spoke of how important the Protection and Advocacy program has been to him personally in finding appropriate and responsive programs for his daughter. He further emphasized how important it is for protection and advocacy agencies to maintain their independence in each state and have a clear mandate to advocate on behalf of all individuals with developmental disabilities.

Dr. Al Healy, Director of the Division of Developmental Disabilities at the University Hospital School at the University of Iowa, spoke on behalf of the American Association of University Affiliated Programs (AAUAP). Accompanying Dr. Healy was Ms. Kim Hurley, from Volga, Iowa, who is twenty years old and has cerebral palsy. Kim has been a client of the Iowa UAP since she was a child and uses both a motorized wheelchair and an assistive speech device. She is a student in accounting at the University of Northern Iowa. Dr. Healy recommended continued expansion of University Affiliated Programs. He stressed the importance of stability and continuity in the training grants awarded to University Affiliated Programs. He also noted important new areas for future training activities. Ms. Hurley told of how important services she received at the Iowa UAP had been to her. The assistance she has received from the UAP and as a result of assistive technological de-

vices makes it possible for her to achieve what ever she sets her mind to.

Issues raised

The testimony provided during the hearings and for the record revealed a number of issues for consideration in developing amendments to the Act. These issues will be discussed in terms of their relevance to each part of the Act.

The Basic State Grant Program

Part B of the Act provides Federal assistance to States for planning, policy analysis, and advocacy activities which assist in developing a comprehensive system of services and supports for persons with developmental disabilities. Activities conducted through this basic State grant program are organized through State Planning Councils on Developmental Disabilities. The planning, policy analysis and advocacy activities of these Councils have resulted in new or increased State service initiatives such as community based care and community living, case management, employment and supported employment, training of professionals and direct care providers, family support, prevention and early intervention and services for children.

The activities have also resulted in improved use and coordination of Federal funds through policy support for implementation of supported employment, individual and family support, accessible transportation, community health services and social services such as personal attendant care services. These have been accomplished by using the funds available to the Councils as catalytic agents to assist States to better use Federal and State resources to promote independence, productivity and integration into the community of persons with develomental disabilities.

Testimony during the hearings addressed the potential impact of the comprehensive study conducted by the Councils in response to the mandate included in the 1987 Amendments to the Developmental Disabilities Act. Issues which emerged during testimony included the need for an expanded Federal priority area, continuing attention to the problems of individuals who meet the federal definition of developmental disabilities, but who are unserved or underserved in the states, and the need for clarification about the role and responsibilities of the Councils and their relationship to the designated State agency which serves as their "administrative home".

In response to Congressional mandate, Councils in every State and Territory assessed Federal and State programs that provide services to persons with developmental disabilities. They also conducted a survey of consumers, seeking informaiton about their satisfaction with services that were available to them. This comprehensive report came to be known as the "1990 Reports." As Dr. Elizabeth Boggs of New Jersey testified, "The Congressional mandate gave states the opportunity to be visionary in their quest to promote system change and to enhance the planning and coordination of services for people with developmental disabilities." Witnesses pointed out that the intense activity initiated by this study will continue well into this decade and beyond. They emphasized

the importance of these findings in the determination of future policy directions.

Testimony provided by Ken Campbell called for an expansion of one of the Federal priority areas which guide Council activities. He pointed out the fragmented nature of the service system that people with developmental disabilities must deal with in order to facilitate their independence and integration into community life. As he stated, "The 'system' is an entity to consumers, a part of their lives. And it is not always a positive or friendly part." He recommended an expansion of the federal priority on case management, which would emphasize that issues of consumer access, involvement and choice, in concert with system design and integration are pivotal in achieving full independence, productivity and integration into the community for people with developmental disabilities.

Other issues which emerged in oral and written testimony related to the continuing concern for those people with developmental disabilities who remain unserved or underserved. Councils have found that many people are underserved, and services are not fully available or appropriate, or they are unserved and remain outside the service system.

Testimony was provided regarding the need to clarify the Councils independence. The relationship between the Council and the designated State agency was also addressed. At present, most Councils are not designated "State agencies" in State statute, and are technically unable to administer State grant funds. However, Councils must direct the expenditure of such funds so as to carry out the goals of their state plan and the requirements of the Act. Further clarification is needed such that it is clear that Council staff is empowered to act only on behalf of the Council, implementing its decisions rather than being assigned extraneous tasks.

Other technical and administrative issues identified in testimony included the need to clarify matching rate requirements for various activities, update plan requirements so as to include the findings of the Congressionally mandated "1990 Reports", allowing Councils to recommend further gubernatorial review of the placement of Councils within state government if the current designated state agency imposes undue restriction on the Council's ability to carry out their responsibilities, and ensuring that vacancies on the Council are filled in a timely fashion to enable it to carry out its mandated functions.

Protection and advocacy of individual rights

Part C of the Act provides allotments to support a system in each State to protect the legal and human rights of persons with developmental disabilities. These Protection and Advocacy Systems (P&As) represent children and adults with developmental disabilities in special education, child abuse and guardianship issues, abuse and neglect in institutions, access to community services, income benefits, transportation, housing, employment discrimination and accessibility to public structures. In addition to these specific areas of advocacy, P&A Systems in many states have achieved significant systemic reform in the delivery of services to persons with developmental disabilities.

It is the P&As that ensure that the rights of persons with developmental disabilities are protected and that public policy is translated into meaningful action. In 1988, Protection and Advocacy Systems served approximately 61,400 persons in 1988 and 136,960 persons were served by class action suits. In 1989, 70,508 individuals were served. The P&As have been successful in negotiating over 90 percent of their cases without resort to litigation.

Several issues emerged regarding the Protection and Advocacy System. These included the need to clarify the independence of P&A Systems including clarification about appointments to the governing board of a P&A System, clarification about the conditions under which P&A Systems have access to records, and the need for clear process for redesignation of the System within State government.

In terms of the independence of the P&As, Dr. Elizabeth Boggs testified that, "One of the major reasons for the success of the P&A systems has been the underlying principle within the system of conflict-free advocacy and independence. The Governor of each state has the authority to designate an agency to serve as the P&A. However, the Governor must assure that the agency is independent of service providers and able to pursue legal, administrative and other appropriate remedies without interference." Mr. Henry Brown stated, "The watch dog must not be a part of the agency. Our experience here in South Carolina reflects the experience of P&As throughout the country that in order to do our work, the agency must be independent of the service providers and must be free to aggressively advocate on behalf of our children."

Another issue raised was with regard to the difficulty experienced by some systems in reaching clients for whom the system has reason to believe that abuse or neglect may be occurring and that the health and safety of the individual is in serious jeopardy. In cases where the individual has a guardian, existing law requires that the P&A System not become involved if the guardian refuses the assistance offered. Clarification of the conditions under which the P&A System can intervene in these extraordinary circumstances is necessary.

Finally, testimony was offered about the importance of a clear process for redesignation. Witnesses told of several governors who have not properly communicated with the agency about problems they were having with the program and did not give proper notice to the disability community for their input. Without a clear process for redesignation by governors, agencies are subject to undue pressure.

University affliliated programs

Under Part D of the Act, grants are awarded to support a national network of University Affiliated Programs (UAPs) and satellite centers. These programs provide interdisciplinary training, exemplary services, technical assistance, and information dissemination to ensure that there is a professional and paraprofessional work force prepared to meet the service needs of persons with developmental disabilities.

The accomplishments of the UAPs are many. Over 72,000 people with developmental disabilities and their families were served in

UAPs in 1989. Additionally, 2,700 books, journal articles, audio-visual and public awareness documents were disseminated. The equivalent of 50 person years of effort was provided in the form of technical assistance. UAPs were able to generate an additional $21 for every $1 of core administrative funding received through the Developmental Disabilities program. In 1988, three new UAPs were established in Arkansas, Hawaii, and Illinois and one Satellite Center established in Idaho. In 1989, two new UAPs were established including one in New Hampshire and one in Texas. There are currently UAPs in 44 states.

A number of issues emerged during the hearing and for the record regarding UAPs, including the need for maintaining flexibility in the program, expanding the training grant initiative while ensuring stability for training activities under this initiative, the need for further expansion of UAPs, and the need for the creation of a consumer advisory board by each UAP.

The first issue raised concerned the need to ensure continuity in the training initiative created by the 1987 Amendments to the Developmental Disabilities Act. These initiatives were intended to assist the UAPs in focusing on areas of emerging national significance for persons with developmental disabilities and three priority areas were identified: early intervention, aging, and the training of direct care personnel. As Dr. Elizabeth Boggs pointed out in her testimony, "As we approach the new millenium, these next ten years will be critical for the design and delivery of services and other assistance to people with developmental disabilities." She emphasized, however, that ". . . innovations and new initiatives must be coupled with assuring that the basic manpower needs of an expanding service system are met. . . . Only with such commitment can people with developmental disabilities come to enjoy greater independence, productivity and participation. This is the role that UAP's must continue to be empowered to play."

Dr. Al Healy made reference to the training priority in early intervention and offered, as an example of the continuing need, the impact of the Amendments to the Education of the Handicapped Act in 1986 (P.L. 99-457) which authorized early intervention services for infants and toddlers. He cited the Office of Special Education Programs (OSEP) in the Department of Education which recently projected 100,000 infants and toddlers with disabilities who will be eligible to receive interdisciplinary early intervention services as a result of the implementation of P.L. 99-457. Yet, as Dr. Healy points out, over 85% of the states report substantial shortages in those critical disciplines which are necessary to effectively implement the law. However, the initial training programs were supported for only a two year period. Dr. Healy stressed that, "the early intervention personnel needs of this country will not be solved in the next 24 months. In order to keep our collective promise to these infants, Congress, the Department of Education, the Administration on Developmental Disabilities and the UAP national network have got to stick to it over the long haul."

In his testimony, Dr. Charlie Lakin referenced the growing need for training direct care staff. He observed, "At present rates of growth in community service consumers, present staffing patterns and present rates of staff turnover, between the years 1990 and

2000 there will be a total of about 650,000 to 750,000 direct care personnel hired for community residences nationally."

Both Dr. Healy and Dr. Lakin pointed out additional areas of national significance: positive behavior management and assistive technology. Dr. Lakin spoke of the growing numbers of individuals entering community programs who bring with them behaviors that create difficulties in community settings. He strongly emphasized the need for training staff members who work in those settings about the use of positive behavioral interventions. As he pointed out, "Punishment is easily practiced, but it teaches nothing. Worse, it is counter to the recognition of rights and dignity of persons with developmental disabilities which is the heart and soul of the Developmental Disabilities Act."

Witnesses emphasized the utilization of technology as a growing area of importance. Access to and the use of technology are critical to achieving integration for many people with developmental disabilities. Training will help to ensure access and appropriate application of assistive technological devices. Witnesses emphasized that integration and technology together unleash tremendous creativity and significantly enhance the capacity of individuals with developmental disabilities to realize independence and the opportunity to participate fully in society.

Testimony also stressed the importance of continued expansion of the UAP program. Witnesses stressed the importance of ensuring access to the benefits of a UAP for citizens of every state. The quality of the UAP program was emphasized and it was stressed that programmatic quality should serve as the single most important criteria for establishing new UAP programs. Second in importance is the ability of a UAP applicant to demonstrate need for such a program. States with no UAPs should have priority over states who already have UAP programs.

Finally, testimony addressed the need to require the establishment of an advisory council by each UAP. This advisory council would increase opportunities for consumer input, and assist UAPs in their goal toward increasing the supporting the independence, productivity, and integration in the community of persons with developmental disabilities.

Projects of national significance

Part E of the Act provides for grants for demonstration projects to increase and support the independence, productivity and integration into the community of persons with developmental disabilities. These grants are intended to focus on areas of key importance in the field of developmental disabilities. For example, grants have been funded to study the feasibility of national and regional information and referral systems; develop and maintain an ongoing data collection system; provide technical assistance to State Developmental Disabilities Planning Councils, State Protection and Advocacy Systems, and University Affiliated Programs; establish projects in family support, quality of life, culturally sensitive programs, HIV/AIDS, and staff training.

Both oral and written testimony emphasized the importance of the Projects of National Significance. In his testimony, Dr. Charlie Lakin pointed out that data generated as a result of these projects

are used for policy and planning in virtually every state in the nation and by Congress as well. National data on expenditures in developmental disabilities, residential services and employment is collected and disseminated annually. The importance of the technical assistance supported under this program was cited by Mr. Ken Campbell who pointed out the critical role such assistance played with respect to the Congressionally mandated "1990 Reports". The National Consumer Survey conducted by Planning Councils in response to the 1987 Amendments to the Act was also emphasized as being a rich data base which can serve as an ongoing resource to the developmental disabilities field.

An issue that emerged during testimony was the growing need for a national study of the prevalence of developmental disabilities. Witnesses explained to the Subcommittee that preparation for such a survey has begun in the Department of Health and Human Services. They emphasized that a survey of this magnitude was beyond the capacity of the Developmental Disabilities Program to carry out but encouraged support of such a survey through other, more appropriate mechanisms, but urges the Committee to see that there are funds to complete it.

III. Legislative Consideration and Votes in Committee

S. 2753 was introduced on June 19, 1990, by Senator Harkin. Cosponsors include Senators Durenberger, Kennedy, Hatch, Simon, Coats, Adams, Jeffords, Metzenbaum, Akaka, Bingaman, Dodd, Dole, and Cochran. At the request of all members of the Subcommittee on Disability Policy, the bill was considered directly by the Committee on Labor and Human Resources.

S. 2753 was brought for markup at the Committee on Labor and Human Resources on Wednesday, June 27, 1990. At that time, Senator Harkin offered an amendment in the nature of a substitute. Senator Jeffords offered an amendment to the substitute increasing minimum allotments under the basic state grant program. The substitute as amended was adopted by voice vote. The motion to favorably report the bill with an amendment to the Senate was passed unanimously by voice of the Committee.

IV. Explanation of the Bill and Committee Views

FINDINGS AND PURPOSE

The Committee restates its support for the basic findings and purposes of the Act. The refinements to the findings and purposes section of the Act reflect the most up-to-date thinking on information and approaches to enabling persons with developmental disabilities to achieve their maximum potential.

First, Section 2 of the bill modifies Section 101 of the Act and updates the number of persons with developmental disabilities in the United States from two million to three million which more accurately reflects current information.

Secondly, the bill adds "a substantial portion of persons with developmental disabilities remain unserved or underserved" to the findings. This includes people with mental disabilities, physical disabilities or a combination of physical and mental disabilities. Pre-

liminary findings obtained by Developmental Disabilities Planning Councils as a result of the comprehensive report mandated by Congress in the 1987 Amendments to this Act, termed the "1990 Report" further substantiate that many people remain unserved and underserved.

Third the bill specifies, as a purpose of the Act, interdisciplinary training to a broad group of people including professionals, paraprofessionals, family members and individuals with disabilities. Interdisciplinary training is one of the important activities assisted under this Act.

Fourth, the bill adds as a purpose, "to advocate for public policy change and community acceptance to enable all people with developmental disabilities to receive the services, supports and other assistance and opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity and integration into the community." This statement is fundamental to the overall purpose of the Act.

Finally, the bill recognizes the commitment toward enabling all people with developmental disabilities, including those with severe disabilities, to achieve interdependence and inclusion in society, and recognition of contributions other than just productivity. Added purposes include, "to promote the inclusion of all persons with developmental disabilities, including persons with severe disabilities; in community life, to promote the interdependent activity of all persons with developmental disabilities, including persons with severe disabilities; and to recognize the contribution of all persons with developmental disabilities as such persons share their talents at home, school, and work, and in recreation and leisure time."

These concepts move beyond the goals of independence, integration, and productivity. They recognize that persons with disabilities are members of a society in which interdependence and inclusion are reflective of equality and acceptance, and people with developmental disabilities have much more to contribute than only productivity, a term that is primary related to work.

The Committee finds that the program assisted under the Act, Planning Councils, Protection and Advocacy Systems and University Affiliated Programs, have different functions but are inter-related and inter-dependent. The Committee encourages frequent, regular communication and coordination between and among the programs to ensure that state-wide planning considers training, research, and programmatic and legal issues in a wholistic manner. To the extent possible, representatives of each of the programs should be involved as advisors to the activities of the others and should be represented as members of advisory boards or similar bodies where appropriate.

DEFINITIONS

Section 3 of the bill modifies Section 102 and amends the term "developmental disability" in order to more accurately include infants and young children with developmental disabilities. The definition makes reference to severity and chronicity, the inclusion of physical disabilities, mental disabilities or a combination of physi-

cal and mental disabilities, and functional limitations in at least three major life areas. Functional areas referenced in the definition include self care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self sufficiency.

However, four of the functional areas do not apply, or are very limited in their application, to infants and young children. They include self care, self-direction, capacity for independent living, and economic self sufficiency. Therefore, the bill applies the current definition, when applicable, to infants and young children and also clarifies the definition to more accurately reflect current best practice. In addition, the bill recognizes that infants and children may have substantial and recognizable developmental delay from birth, which may not be manifested by functional limitations in three or more areas listed in the definition. Further, the bill recognizes that an infant or young child may have conditions which place them at high risk for developmental disabilities. In this latter instance, it is the intent of the committee that the application of the definition will ensure early intervention services be available to infants and young children so that they can mitigate against or minimize the impact of any subsequent developmental disability.

The bill modifies the term "integration" in order to add "employment" to "community activities" as a part of the definition. An important national goal is enhancing the opportunities for employment for persons with developmental disabilities. The opportunity for meaningful employment is a critical part of the effort toward promoting integration, independence and productivity for persons with developmental disabilities.

The bill further modifies the term "integration" by adding "use of the same community resources by people with developmental disabilities living, learning, working, and enjoying life in regular contact with citizens without disabilities" and "development of friendships and relationships with persons without disabilities. In this same definition, the term "nondisabled citizen" is changed to "citizens without disabilities" in order to reflect current and appropriate language. The term "home-like settings" is removed for the same purpose. All people reside in homes.

The term "priority area activities" is clarified in order to more accurately specify the beneficiaries of such activities. The term "local, state, and federal" is added to describe "policy makers".

The Committee finds that for model demonstrations authorized as a priority area activity, funds allocated under Part B of this Act may be used for direct services only when doing so is part of a short-term strategy in advocating for systems change or on-going funding from sources other than this Act for such services. It is not the intention of Congress that these funds be used as a long-term funding source for services. It should be further noted that the extensive statutory definitions of services and supports are provided as guides to the states and are intended to serve as goals toward which service providers should strive and should be used by Planning Councils to evaluate how well services address the independence, productivity, and integration into the community of people with developmental disabilities.

The bill modifies the term "case management" under the definition of "Federal priority areas". The priority area for case management is expanded and renamed "systems coordination and community education" and a definition is added. The function of case management is to integrate appropriate services for an individual when such services are provided by multiple agencies with differing philosophies, definitions, and rules. However, case management on behalf of an individual is insufficient when the system is structured in such a way as to prohibit effective case management. Therefore, this priority area is expanded to assist Councils in addressing the broad structural issues which are critical to ultimately achieving effective case management. It further emphasizes the importance of educating community members about services and systems, and helping people to organize to meet the needs of people with developmental disabilities.

The bill adds a definition for the term "protection and advocacy system" and expands the definition for assistive technology in order to conform with the definition in the Technology-Related Assistance Act, P.L. 100-407.

The bill continues to recognize the central role the family and members of the community, including friends and neighbors, can play in enhancing the lives of persons with developmental disabilities. The bill adds a definition for "individual supports", and a definition for "community supports". This addition of two new definitions recognizes the importance of enabling an individual with developmental disabilities to be independent, productive, and integrated into their community, and the need to assist communities in being more responsive to the needs of people with developmental disabilities and their families; develop local networks which can provide informal support, and make communities more accessible. These definitions focus on capacity, rather than limitations, of persons with developmental disabilities. Indeed, the Committee recognizes that social relationships beyond the family are critically important, and that supporting individuals with disabilities in the forming and maintaining of relationships with friends, neighbors, and other members of the community, in accordance with the desires and interest of the individual with developmental disabilities, is appropriate and consistent with the goals of the Act. These definitions are meant to be illustrative and are not all inclusive.

The bill adds the term "prevention" and defines it as "activities which address the causes of developmental disabilities and the exacerbation of functional limitations, such as activities to (A) eliminate or reduce the factors which cause or predispose individuals to developmental disabilities or which increase the prevalence of developmental disabilities, (B) increase the early identification of existing problems to eliminate circumstances that create or increase functional limitations; and (C) mitigate against the effects of developmental disabilities." Prevention encompasses a broad range of activities which could be considered under the Federal priority areas of child-development, community living, employment, systems coordination and community education, or it could be considered under a state priority area. Such activities should be consistent with state plan objectives in any of the priority areas for which they are deemed by the Council to be appropriate.

FEDERAL SHARE

Section 4 of the bill amends Section 103 by amending the determination of the Federal poverty area matching rate. It specifies that people living in poverty areas must be beneficiaries of services or products provided by a grantee claiming the poverty area matching rate. Grantees in some states who are serving poverty areas are not being allowed to use poverty area matching rates in determining the Federal share of grants for technical reasons such as a mailing addres that is not in the poverty area or a main office not located in a poverty area.

Section 103 is further amended to specify that the non-Federal portion of any project or program assisted by a grant or allotment under Part B of this Act may be considered as provided in kind.

REPORTS

Section 5 of the bill amends the reporting requirements of Section 107(a) by specifying that the State Planning Councils must include in the report prepared pursuant to this Section a response to significant actions taken with regard to "any intermediate care facility in such State, and with respect to each annual survey report prepared pursuant to section 1902(a)(31)(C) of the Social Security Act and each correction or reduction plan prepared pursuant to section 1922 of such Act." This is consistent with the Council's advocacy responsibility and primarily clarifies that responsibility.

The bill further amends Section 107 (a) and (c) to reflect the Committee's strong support for the functional definition of the term "persons with developmental disabilities", which has been in the Act since 1978. Under this definition, a broad range of persons with developmental disabilities attributable to physical disability, mental disability, or a combination of physical and mental disabilities are included. Specifically, the term "unserved and underserved groups" is added. It is the Committee's intent that the basic State grant program be a vehicle for planning and advocacy for a broad spectrum of developmental disabilities, and that particular attention be given to those individuals who are unserved or underserved.

Section 107(b) is amended to update the name of the National Council on the Handicapped to the National Council on Disability.

RESPONSIBILITIES OF THE SECRETARY

Section 6 of the bill amends Section 108 of the Act by adding the Administration on Children, Youth and Families, the Administration on Aging, and the Health Resources and Services Administration of the Department of Health and Human Services to the membership of the interagency committee established by the Secretary of Health and Human Services under the provisions of this section. The Administration on Developmental Disabilities of the Department of Health and Human Services, the Office of Special Education and Rehabilitative Services of the Department of Education, and the Department of Labor remain as members along with other agencies as the Secretary of Health and Human Services and the Secretary of Education may determine.

Persons with developmental disabilities benefit from services and supports which are the responsibility of multiple agencies to provide. The Committee finds, for example, that a substantial number of children and families currently served by programs assisted by the Administration on Children, Youth and Families are children with developmental disabilities. As the population of persons with developmental disabilities ages, they will seek a growing number of services through programs assisted by the Administration on Aging. The Health Resources and Services Administration is responsible for some health programs serving persons with developmental disabilities. The Committee finds that in order for persons with developmental disabilities to have access to comprehensive services, the Administrations named must join with those all ready serving on the interagency committee and work to improve coordination of service delivery.

The bill also adds requirements that the interagency committee organize their work so as to address cross cutting issues of national concern, and specifies that these issues reflect the findings of the "1990 Report", mandated by Congress under the 1987 Amendments to this Act.

RIGHTS OF THE DEVELOPMENTALLY DISABLED

Section 7 of the bill amends the title of Section 110 from "Rights of the Developmentally Disabled" to "Rights of Persons with Developmental Disabilities". This is consistent with accepted language and practice.

Section 110 is further amended by updating the reference to regulations applicable to intermediate care facilities for the mentally retarded (30 Fed. Reg. pt. II) from January 1, 1974 to June 3, 1988.

PART B—FEDERAL ASSISTANCE FOR PLANNING PRIORITY AREA ACTIVITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

Section 8 of the bill amends the provision in Section 122 of the Act which describes the relationship between the Planning Council and the designated state agency in order to define the role of the state agency with respect to the Council and to clarify the relationship. "Such designated State agency shall, on behalf of the State receive and account for and, at the direction of the Council, disburse funds pursuant to Part B, and shall provide administrative support services to the State Planning Council." The role of the designated state agency with respect to basic state grant funds is limited to making sure that the state laws are applied as appropriate. The Council must maintain the right to direct the expenditure of those funds in order to carry out its designated policy analysis, planning and advocacy role, and in accordance with its plan so long as it is consistent with State law.

Second, the bill amends Section 122(d)(1) by adding the phrase, "State contributions pursuant to this paragraph may be counted as part of such State's non-Federal share of allotments under this part". Some States have not been allowed to use all state contributions in claculating their portion of the non-Federal match required as a part of this Act. This will clarify that all states may use all state expenditures for the exercise of the functions of the

state designated agency in support of Council activities, pursuant to Section 122, as a part of the State's non-Federal share of allotments.

Third, the bill adds "child welfare" to the programs which Councils must review which also include education, job training, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, aging, programs for children with special health care needs, housing, comprehensive health and mental health. The bill expands the scope of responsibility for Councils with regard to reviewing other state plans by adding the terms "program" and "or policies affecting" when a reference is made to plans, as appropriate. Not all federally assisted state programs who have responsibility for services which benefit persons with developmental disabilities are required to develop a state plan. The Committee finds that, in those instances when such an agency does not publish a state plan, the Council must review relevant policy documents reports, and programs which pertian to that agency, as a means of analyzing their impact on enhancing opportunities for independence, integration and productivity for persons with developmental disabilities. Councils should specify in their State Plans which federally assisted programs without state plans they will review, based on which state plan objectives, and describe how such review is seen as a component of a larger strategy of investigation into the operation of the service delivery system on behalf of all persons with developmental disabilities.

Fourth, the bill adds a requirement such that a state plan must "assess and, if appropriate, update the findings of the report conducted pursuant to subsection (f), and report on any progress achieved concerning issues identified in the report conducted pursuant to such subsection in the previous fiscal year". Councils carried out an extensive and comprehensive review, analysis and written report on the eligibility for, extent, scope and effectiveness of services provided by and functions performed by all State agencies impacting on the lives of persons with developmental disabilities (including agencies which provide public assistance) attributable to a physical impairment, a mental impairment, or a combination of physical and mental impairments to achieve the goals of independence, productivity, and integration into the community. This comprehensive report is referred to as the "1990 Report". Councils should, as a part of their planning process, review their findings and report on the current status with respect to those findings and use these findings to address issues of concern which were identified by their analysis. This includes all subpopulations of persons with devleopmental disabilities including the unserved and underserved. This Committee does not intend for Councils to conduct a comprehensive review, analysis and written report, similar to the "1990 Report", each year but to consider their findings as they develop their state plans and to report on progress made in reaching their recommendations in their annual report.

Fifth, Section 122(b)(5)(D) is further amended to add "and activities which address the implementation of recommendations made in the report described in subsection (f), including recommendations which address unserved and underserved populations" in

order to further include the findings of the "1990 Report" in state planning activities.

Finally, the bill amends Section 122(e) by adding "After October 1, 1990, the Planning Council may issue a request for a review of the designation of the designated State agency by the Governor". This allows Councils, at their initiation, to request that the Governor review the designated state agency, for purposes of determining the appropriateness of such designation. The determination is initiated by the Planning Council and is made at the Governor's discretion. However, the Governor must make an independent assessment of the impact the current designation on the ability of the Council to serve as an advocate for persons with developmental disabilities. Before a decision is made the Governor must consider the comments of the general public and the non-agency members of the State Planning Council.

STATE PLANNING COUNCILS

Section 9 of the bill clarifies the primary function of the State Planning Council under section 124 of the Act to serve as an advocate for persons with developmental disabilities, to conduct public policy analysis, and do planning. This is consistent with the role and function of Councils as stated throughout the Act.

The Committee finds that far too frequently when vacancies occur on Councils, Governors do not appoint new members in a timely way. This can affect the required membership balance on the Council, and diminishes the effectiveness of the Council. The Committee urges Governors to make such appointments within a reasonable time frame and with input from the Council and other interested disability organizations.

Second, Section 124(c)(1) is amended by expanding the word "hire" to include "fund all activities under this part (except administrative costs as defined in Section 122(d)(1)) and to hire". Most Council staff members are state public employees and, while personnel costs are covered by Federal funds, States have sometimes prevented the Council from utilizing funds alloted under this Act in order to hire new Council staff or fill staff vacancies if State governments have placed a freeze on state hiring. If adequate staff are not available to Councils, they are prohibited from carrying out their responsibilities in a timely and effective manner. It is the Committee's intent that Councils maintain the authority to hire staff when such staff are paid from funds alloted under this Act, even when the State has invoked a freeze on State hiring.

Third, the bill amends Section 124(c) to add "Each State Planning Council shall, consistent with State law, hire a Director of the State Planning Council who shall be supervised and evaluated by the State Planning Council and who shall hire and supervise the staff of the State Planning Council". The Director of the State Planning Council is responsible for informing the designated state agency of Council practices and ensuring that they are consistent with state law and administrative code. However, the Director must be responsible to the Council Chairperson for all other duties.

STATE ALLOTMENTS

Section 125 of the Act is amended to increase the minimum allotment for low population states from $350,000 to $400,000 when the appropriation level reaches $65,000,000. The bill also directs the Secretary to increase the minimum allotment administratively when the increase in the appropriations is greater than the Consumer Price Index.

AUTHORIZATION OF APPROPRIATIONS

Section 10 of the bill amends Section 130 of the Act to authorize to be appropriated $81,270,000 for fiscal year 1991, $85,335,000 for fiscal year 1992, $89,600,175 for fiscal year 1993, and $94,080,190 for fiscal year 1994. The authorization level recommended by the Committee for each of the fiscal years 1991 through 1994 constitute a 5% increase over the current authorization. These increases are needed because the developmental disabilities program is the only Federal program designed to address the comprehensive needs of persons with developmental disabilities, the most severely disabled group in our Nation. They are also needed to enable the States to implement the important new initiatives included in this bill and the "1990 Report".

PART C—PROTECTION AND ADVOCACY OF INDIVIDUAL RIGHTS

Section 11 of the bill amends Section 142 pertaining to the Protection and Advocacy Systems in several respects. First, the bill clarifies the conditions under which protection and advocacy systems have access to records. Language is added which specifies that "any person with a developmental disability who has a legal guardian, conservator, or other legal representative with respect to whom a complaint has been received by the system or with respect to whom there is probable cause to believe the health or safety of the individual is in serious and immediate jeopardy whenever (I) such representatives have been contacted by such system upon receipt of the name and address of such representatives; (II) such system has offered assistance to such representatives to resolve the situation, and (III) such representatives have declined to act on behalf of the person."

Under current law, a system has access to all records of any person with develomental disabilities who, by reason of the mental or physical condition of such person, is unable to authorize the system to have such access; who does not have a legal guardian, conservator, or other legal representative, or for whom the legal guardian is the state; and with respect to whom a complaint has been received by the system or with respect to whom there is probable cause to believe that such person has been subject to abuse or neglect. The bill clarifies that a system may conclude there is "probable cause" based on monitoring or other activities.

Second, the bill amends the term "records" in Section 142 and clarifies it by adding "As used in this section, the term "records" includes reports prepared by or received by any staff of a facility rendering care or treatment, or reports prepared by an agency or staff person charged with investigating reports of incidents of abuse or neglect, injury or death occurring at such facility that de-

scribes incidents of abuse, neglect, injury or death occurring at such facility and the steps taken to investigate such incidents, and discharge planning records."

Third, Section 142 is amended in order to clarify the process by which the Governor may redesignate the State agency implementing the Protection and Advocacy System. The bill requires that "(A) notice has been given of the intention to make such redesignation to the agency that is serving as the system including the good cause for such redesignation and the agency has been given an opportunity to respond to the assertion that good cause has been shown; (B) timely notice and opportunity for public comment in an accessible format has been given to persons with developmental disabilities or their representatives; and (C) the system has the opportunity to appeal to the Secretary that the redesignation was not for good cause."

Fourth, clarification is made about who may be appointed to a governing board of a Protection and Advocacy system and now conforms with the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (P.L. 99-319). Specifically, members must be selected no later than 60 days following a vacancy, and must be broadly representative or knowledgeable about the needs of the clients served by the system. In the case of a governing authority organized as a private nonprofit entity, members must broadly represent or be knowledgeable about the needs of the clients served by the system. The Committee believes that to assure conflict-free advocacy services, the governing boards of Protection and Advocacy Systems should not consist of providers of services to persons with developmental disabilities who may potentially be the focus of the advocacy of the Protection and Advocacy System on behalf of the person. However, the Committee does not intend to eliminate providers of legal or advocacy services which do not provide other essential direct services to people with developmental disabilities. The Committee recommends that consumers be appointed to Boards whenever possible.

Fifth, the bill amends Section 142 by adding, "Nothing in this Act shall preclude the systems described under this section from bringing a suit on behalf of persons with developmental disabilities against a State or agencies or instrumentalities of a State." This has been a longstanding responsibility of P&A Systems and the purpose of this amendment is to clarify that responsibility.

Sixth, the bill amends Section 142 by adding, "Amounts received pursuant to paragraph (1) through court judgments and used by the system are limited to furthering the purpose of this part and shall not be used to augment payments to legal contractors or to award personal bonuses." P&A Systems may receive funds as a result of court judgements. Expenditures of these funds must be limited to the purposes of the P&A System as specified in Section 142 of the Act.

Finally, the bill amends Section 142 by adding, "Notwithstanding any other provision of law, the Secretary shall pay directly to any system which complies with the provisions of this section the amount of such system's allotment under this section, unless the system delegates otherwise." The Committee understands that P&A Systems, in some instances, do already receive allotments di-

rectly. The Committee intends that such practice continue unless the P&A System delegates the payment to occur otherwise.

AUTHORIZATION OF APPROPRIATIONS

Section 12 of the bill amends Section 143 to authorize to be appropriated $27,000,000 for fiscal year 1991, $28,350,000 for fiscal year 1992, $29,770,000 for fiscal year 1993, and $31,258,500 for fiscal year 1994. The authorization recommended by the Committee for FY1991 over current level is 12%. Many P&A Systems around the country are facing growing waiting lists and must turn away large numbers of eligible clients. Five percent increases are recommended for each subsequent year.

PART D—UNIVERSITY AFFILIATED PROGRAMS

Section 13 of the bill retains the Secretary's authority under section 152(b) to make grants to UAPs receiving core funding for the purpose of providing service-related training and conducting applied research. Service-related training may be provided to persons with developmental disabilities, family members of such persons, or professionals, volunteers, or other personnel.

The bill makes several changes to Section 152(b). First the Committee recognizes the continuing need for service related training and the importance of ensuring flexibility such that UAPs will train in topical areas that address critical needs within their own State. Further, the Committee recognizes the need for stability so that UAP training activities will assure adequate numbers of staff in community settings in order to promote opportunities for independence, integration, and productivity for persons with developmental disabilities. The Committee is also aware that UAPs are successful in securing additional resources for training programs assisted under this Act from other entities, when there is assurance of flexibility and stability. Finally, the Committee recognizes the need for assuring the highest quality of training through an effective review and monitoring process.

Section 13 of the bill amends Section 152(b) by awarding training grants for a period of three years at which time UPAs who wish to do so may reapply on a competitive basis. Thus the continuity of the training grant programs are strengthened and the likelihood that state and local service agencies will invest staff and resources in them is enhanced. UAPs may submit applications for training grants that incorporate more than one priority area.

UAPs will have a three year period in which to sufficiently develop training programs and involve representatives of those Agencies who provide services to persons with developmental disabilities. While the development of curricula and other training materials is of critical importance, the impact of these training programs is largely dependent upon the involvement of the State Mental Retardation/Developmental Disabilities Agencies, State Departments of Education, the State Children and Family Service Agency, the State Interagency Committee which has the responsibility to implement the early intervention programs authorized by P.L. 99-457, and the various state agencies responsible for administering the Older Americans Act. Their active participation helps to

ensure that training is actually delivered to the professionals, direct care staff and families who most need it.

Moreover, in order to sustain a maximum systemic impact, it is expected that the Secretary will make training grants of $90,000 for each UAP, if resources are available, and if UAP applicants sufficiently meet quality criteria. The bill provides training grant awards to exceed $90,000 "if the Secretary determines that such grants are of sufficient scope and quality so as to address issues of national significance" as identified in the "1990 Report". Such awards may be up to $150,000 if sufficient funds are available.

The Committee finds that a system of effective peer review is critical in order to ensure that training programs created under Section 152(b) are of the highest quality. Therefore, the bill specifies that training grant applications and programs be reviewed utilizing a peer review process. The criteria by which reviews will be conducted requires that training be "competency and value based; designed to facilitate independence, productivity, and integration for persons with developmental disabilities; evaluated utilizing state of the art evaluation techniques in the programmatic area selected;" and that core training "shall represent state of the art techniques in areas of critical shortage of personnel which are identified through consultation with the citizens advisory group designated pursuant to subsection (f) and the State Planning Council; be conducted in consultation with the citizens advisory group designated under subsection (f) and the State Planning Council; be integrated into the appropriate university affiliated program and university curriculum; be integrated with relevant state agencies in order to achieve an impact on state-wide personnel and service needs; to the extent practicable, be conducted in environments where services are actually delivered; and to the extent possible, be interdisciplinary in nature." Community based practica constitute training conducted in environments where services are delivered. Quality criteria supercede any quality standards promulgated by the Secretary prior to the date of enactment.

The bill provides that if appropriately convened peer review panels determine that applications submitted by University Affiliated Programs in any fiscal year for core training grants insufficiently address quality criteria the Secretary may utilize amounts which become available as a result of not awarding grants to such applicants to fund other University Affiliated Programs in excess of $90,000, up to the $150,000, under the conditions specified. Further, "The Secretary may make such awards for a period not to exceed 3 years to applicants whose applications are determined to be of minimal quality by peer review".

The Committee recognizes that training initiatives begun under the 1987 Amendments to this Act are still of great importance nationwide. Therefore, the bill continues to include early intervention programs, programs for the elderly, and community based service programs as priority areas. However, the Committee also recognizes that there are two new priorities of emerging national significance. They are positive behavior management programs, and assistive technology programs.

The Committee also recognizes that UAPs must have the flexibility to address issues of that are of significance to their own State,

but may not be of primary concern nationwide, or may be unique to their State. Therefore, an additional priority area is added which allows UAPs to submit applications for training grants in areas that they have determined to be of significance in their own state or region. The UAP is encouraged to consult with the Planning Council and the consumer advisor board established by this bill in making such determination.

The Committee does not intend that the list of priority training areas be mandatory, comprehensive or all inclusive. It is distinctly possible that the Secretary may not receive applications in every training area listed in statute.

Finally, the bill adds a requirement that "The Secretary shall only make grants under this section to university affiliated programs which establish a consumer advisory committee comprised of consumers, family members, representatives of State protection and advocacy systems, developmental disabilities councils (including State service agency directors), local agencies, and private nonprofit groups concerned with providing services for persons with developmental disabilities." A consumer advisory committee will provide another important avenue for consumer input to UAPs as they make decisions regarding training initiatives, and develop and implement those initiatives.

APPLICATIONS

The Committee finds that the requirement for on site peer review with respect to administrative core awards is an ongoing, existing practice. Site visits are commonly designed to answer four distinct questions First, what are the specific outcome of UAP training, exemplary service and community-based technical assistance activities? Second, what impact are UAP personnel training programs having on the service delivery system statewide? Third, is the UAP producing innovative training practices and service models which are easily replicable in other States. Fourth, is the UAP in full compliance with current quality standards?

If the peer review committee finds program impact and outcome to be satisfactory, the overall administrative structure of the UAP is generally beyond the purview of the peer review and site visit process. Specifically, issues concerning the university reporting system or lines of authority outside the organizational structure of the UAP being examined are not relevant unless they directly impede the program's ability to fulfill its statutory mandates.

The Committee recognizes the importance of providing the benefits of UAP programs to all States. Currently there are 44 States who have UAP programs. The bill retains the Secretary's authority under Section 153 to continue the expansion of the UAP program. Those States without a UAP program will be given first priority and the Secretary shall continue to give priority to proposed UAPs that serve rural as well as urban regions with high concentrations of poverty and minority populations.

However, the Committee also recognizes that such expansion should be based primarily on receiving quality applications for new UAP programs. Second, applications for new UAP programs must adequately demonstrate need. If no applications are received from

States without a UAP or the applications from such States are not of sufficient quality, those states who already have UAPs and have submitted an application for an additional UAP may be considered. In all cases applicants must adequately demonstrate need for the UAP.

AUTHORIZATION OF APPROPRIATIONS

Section 15 of the bill amends section 154 of the Act to authorize to be appropriated for core administrative funding $11,400,000 for fiscal year 1991, $12,390,000 for fiscal year 1992, $13,430,000 for fiscal year 1993, and $14,310,000 for fiscal year 1994. The bill also includes a separate line item for core training funds which are authorized to be appropriated at $7,000,000 for fiscal year 1991, $8,652,000 for fiscal year 1992, $10,386,000 for fiscal year 1993, and $12,050,000 for fiscal year 1994. The Committee anticipates that administrative core grants made on or before July 1, 1989 shall be maintained at their current level.

The authorization level recommended by the Committee for FY1991 represents a 12% increase over the current authorization level, a 14% increase for FY1992, a 13% increase for FY1993, and an 11% increase for FY1994. These increases are necesasry because this is the only Federal program designed to support a comprehensive and organized program of exemplary services and training for, among other things, allied health professionals, parents and physicians who provide services to persons with developmental disabilities. These authorization levels are also needed to implement the expansion of the network into States that do not have UAPs and satellites to provide specialized training and services in areas of emerging national significance.

PROJECTS OF NATIONAL SIGNIFICANCE

Section 16 of the bill amends section 161 of the act by clarifying the purpose to say, "and to support the development of national and State policy which enhances the independence, productivity, and integration of persons with developmental disabilities through data collection and analysis, technical assistance to program components, technical assistance for the development of information and referral systems, educating policymakers, Federal interagency initiatives, and the enhancement of minority participation in public and private sector initiatives in developmental disabilities." These are types of activities which support the overall purposes of the Special Project Grants, as well as the purpose of the Act.

Section 161(a)(2) is further amended changing existing language to read "technical assistance (including research, training, and evaluation in connection with such projects) which expand or improve the functions of the State Planning Council, the functions performed by university affiliated programs and satellite centers under Part D, and protection and advocacy system described in section 142." The changes are intended to remove the words "and demonstration projects" after the term "technical assistance", and use the phrase "which expand or improve" instead of the phrase "which hold promise". Technical assistance, as specified in this provision, has been provided in an effective manner since the 1987

Amendments to the Act. Therefore, it is not necessary to continue to classify activities under this provision as "demonstration projects" or suggest that they must be tested in order to see if the "hold promise". Rather, their success warrants continuation and reference as ongoing, proven activities of worth. The Committee recommends that funding under this section provide for the development of ongoing, stable technical support for the programs named in order to fully enhance their capacity over time.

Section 162 is further amended by inserting "promote the development of regional and national information and referral networks" with respect to information and referral systems. A feasibility study of regional and national systems for information and referral was conducted as a part of the 1987 Amendments to this Act. This modification recognizes the continuing importance of information and referral systems.

Section 162 is further amended to add "improve supportive living and quality of life opportunities which enhance recreation, leisure and fitness," as appropriate to consider within Projects of National Significance. The Committee recognizes that individuals with developmental disabilities have a tremendous need for physical fitness enhancement. Improving physical fitness components such as muscular strength, muscular endurance and joint flexibility may play a key role in increased employment opportunities and job productivity. Moreover, improvements to one's fitness and enjoyment of leisure and recreational pursuits are major steps toward improving physical and mental health. Therefore, the Committee recommends that the Secretary consider projects which are designed to improve supportive living and quality of life opportunities which enhance recreation, leisure, and fitness for persons with developmental disabilities.

The Committee finds that access to and eligibility for services and supports is an extremely complex one and has been investigated in depth by Planning Councils as part of their "1990 Report". Most States do not have legislation which uses the Federal functional definition of developmental disabilities for State-financed service eligibility. Each State has had difficulties in implementation. Other States have somewhat similar definitions. As a result of conducting the "1990 Report", some Planning Councils are working toward the adoption of functional definitions as a means of serving the unserved and underserved populations of people with developmental disabilities.

The Committee recommends that the Secretary give consideration to a grant of national significance which would assist States to develop measures to assess functional limitations, which more and more frequently are used by State and Federal programs to establish eligibility in lieu of categorical disabilities. The States which have already adopted such definitions, and those considering such change, should be involved in a study of this nature. Clarification of these issues would also provide Planning Councils, Protection and Advocacy Agencies, and University Affiliated Programs with further information to review and would enhance their advocacy for all persons who meet the Federal functional definition.

Further, the Committee finds that Planning Councils have completed a comprehensive analysis of programs and policies affecting

persons with developmental disabilities and a comprehensive consumer survey in accomplishing the "1990 Report". The Committee recommends that the Secretary consider the data collection problems identified by Planning Councils in accomplishing the "1990 Report" when developing the goals and workplan for the future development of data collection and analysis systems, including varying eligibility criteria and other factors which tend to exclude or fail to take into account unserved and underserved groups of people with developmental disabilities.

In addition, the Committee recommends that the Secretary consider a grant of national significance which would provide for ongoing follow-up and research on the results of the National Consumer Survey. In all, over 14,000 persons with developmental disabilities were interviewed across the United States. Information that has been gathered from these individuals is a valuable source for shaping future federal and state disability policy.

Finally, while the Committee has heard that there is a significant increase in the prevalence of developmental disabilities, accurate figures do not exist. The Committee also finds that there has never been a national study of the prevalence of developmental disabilities, nor has there ever been data elements included in any other national survey which would permit accurate estimation of the prevalence of developmental disabilities. The Committee finds that such a project is beyond the scope of Projects of National Significance under this Act, but urges the Secretary to fund such a survey under other programs.

AUTHORIZATION OF APPROPRIATIONS

Section 18 of the bill amends section 163 of the Act to authorize to be appropriated $3,900,000 for fiscal year 1991, $4,095,525 for fiscal year 1992, $4,299,750 for fiscal year 1993, and $4,514,800 for fiscal year 1994. This represents a 7% increase over current level, and a 5% increase for each of subsequent years. These increases are necessary in order to maintain the national data collection, information and referral, technical assistance activities, and the development of innovative projects of national significance.

V. Regulatory Impact

The Committee has determined that there will be minimal increases in the regulatory burden imposed by this bill.

VI. Cost Estimate

U.S. Congress,
Congressional Budget Office,
Washington, DC, June 29, 1990.

Hon. Edward M. Kennedy,
Chairman, Committee on Labor and Human Resources,
U.S. Senate, Washington, DC.

Dear Mr. Chairman: The Congressional Budget Office has prepared the attached cost estimate for a bill to reauthorize the Developmental Disabilities Assistance and Bill of Rights Act, as ordered

reported by the Senate Committee on Labor and Human Resources on June 27, 1990.

If you wish further details on this cost estimate we will be pleased to provide them.

Sincerely,

ROBERT F. HALE
(For Robert D. Reischauer).

Attachments.

CONGRESSIONAL BUDGET OFFICE COST ESTIMATE

1. Bill number: S. 2753.

2. Bill title: Developmental Disabilities Assistance and Bill of Rights Act of 1990.

3. Bill status: As ordered reported by the Senate Committee on Labor and Human Resources on June 27, 1990.

4. Bill purpose: This bill reauthorizes the Developmental Disabilities Assistance and Bill of Rights Act.

5. Estimated cost to the Federal Government:

[By fiscal years, in millions of dollars]

	1991	1992	1993	1994	1995
Authorizations					
State allotments:					
Authorization level	81.3	85.3	89.6	94.1	—
Estimated outlays	62.6	84.4	88.6	93.1	21.6
Grants to meet State system requirements:					
Authorization level	27.0	28.4	29.8	31.3	—
Estimated outlays	20.8	28.0	29.4	30.9	7.2
University affiliated programs:					
Authorization level	11.4	12.4	13.4	14.3	—
Estimated outlays	1.4	10.5	12.4	13.4	12.5
Grants to support university affiliated program projects:					
Authorization level	7.0	8.7	10.4	12.1	—
Estimated outlays	0.8	6.6	8.7	10.4	10.5
Grants to public and private nonprofit entities:					
Authorization level	3.9	4.1	4.3	4.5	—
Estimated outlays	0.4	3.6	4.1	4.3	4.0
Bill totals:					
Authorization level	130.6	138.8	147.5	156.2	—
Estimated outlays	86.0	133.1	143.3	152.1	55.8

The costs of this bill fall in Function 500.

Basis of estimate: This bill reauthorizes the Developmental Disabilities Asssistance and Bill of Rights Act of 1990. The authorization levels for 1991–1994 for each subsection are stated in the bill. Estimated total outlays assume full appropriation of authorized levels and reflect the current spending patterns of each agency.

6. Estimated cost to State and local government: The Federal share of all projects supported by grants cannot exceed 75 percent of the aggregate costs, except where a project is located in an urban or rural poverty area. In that case, the federal share may not exceed 90 percent of the aggregate costs. States, local governments, or private entities must assume the remainder of project costs.

7. Estimate comparison: None.

8. Previous CBO estimate: None.
9. Estimate prepared by: Diane Celuch.
10. Estimate approved by: C.G. Nuckols for James L. Blum, Assistant Director for Budget Analysis.

VII. Section-by-Section Analysis

Section 1. This section specifies that references in the bill to a section of "the Act" are to the Developmental Disabilities Assistance and Bill of Rights Act.

TITLE I—GENERAL PROVISIONS

Section 2. This section updates the findings section of the Act to reflect the most up-to-date thinking in the field regarding persons with developmental disabilities.

The findings are updated to reflect the increased number of persons with developmental disabilities. Secondly, it is recognized that many persons with developmental disabilities remain unserved or underserved.

The purpose section of the Act is revised to recognize interdisciplinary training, and to add concepts which address interdependence and inclusion of persons with developmental disabilities and to recognize their contribution beyond work, such as their ability to share talents at home and school, and during recreation and leisure time.

Section 3. This section amends the term "developmental disabilities" and adds a new section to the definition that more accurately includes infants and young children with developmental disabilities. The definition of "integration" is modified to add "community activities" and to recognize that integration involves the "use of the same community resources", as well as the "development of friendships and relationships with persons without disabilities".

This section also clarifies the term "priority area activities" by amplifying the description of "policy makers" to include "local, state and federal"; and expands the priority area of "case management" and renames it "systems coordination and community education".

The terms "protection and advocacy system", individual supports", "community supports", and "prevention" are added and defined, and the definition of "assistive technology" is modified to conform with the definition in the Technology-Related Assistance Act, P.L. 100-407.

Section 4 amends the method by which Federal poverty area matching rates are determined in order to allow grantees who are serving poverty areas, but whose addresses are not in the poverty area, to claim the poverty area matching rate; and amends the requirement regarding the use of non-Federal match by states in order to allow all non-Federal portions of any project or program assisted by a grant allotment under this Act to be considered in kind.

Section 5 amends Section 107 in order to clarify the responsibility of Councils to review significant actions taken, including correction or reduction plans, with respect to intermediate care facilities for the mentally retarded. This section is further amended by

adding the term "unserved and underserved groups" as a part of reporting requirements. The name of the National Council on the Handicapped is updated to the National Council on Disability in this section.

Section 6 amends Section 108 by adding the Adminstration on Children, Youth, and Families; the Administration on Aging, and the Health Resources and Services Administration of the Department of Health and Human Services to the membership of the interagency committees established by the Secretary of Health of Human Services. This section also adds requirements that the interagency committee organize their work so as to address cross cutting issues of national significance and provides for public notification of meetings.

Section 7 amends Section 109 by correcting the reference to the Rehabilitation Act of 1973.

Section 8 amends the Title of Section 110 of the Act by changing it from "Rights of the Developmentally Disabled to "Rights of Persons with Developmental Disabilities" in order to reflect accepted practice. The reference to regulations applicable to intermediate care facilities for the mentally retarded is updated.

TITLE II—STATE ASSISTANCE PROGRAM

Section 9 amends Section 121 by inserting "and their families" in the purpose.

Section 10 amends Section 122 in order to clarify the relationship between the Council and the designated State agency with respect to receiving, accounting for, and disbursing funds and with respect to the use of state's non-Federal share as non-Federal match.

This section adds child welfare to the programs which Councils must review, and clarifies that such reviews take place in instances when an agency does not have a state plan as well as when they do.

The State Plan requirements are expanded to add a requirement to assess and, if appropriate, update the findings of the comprehensive study and analysis conducted by Planning Councils as mandated by the 1987 Amendments to the Act.

This section is also amended in order to allow the Planning Council to issue a request for review of the designation of the designated state agency by the Governor.

Section 11 amends Section 124 by clarifing the primary function of the State Planning Council as serving as an advocate of persons with developmental disabilities, conducting public policy analysis, and planning. This section also clarifies that Planning Councils may use Federal funds allocated under this Act to hire Council staff, even when a freeze on State hiring exists and that the Planning Council is responsible for hiring and supervising the Director of the Council.

Section 12. This section increases the minimum allotment for small States from $350,000 to $400,000 when the appropriation level reaches $65,000,000 and directs the Secretary to increase the minimum allotment administratively when the increase in the appropriations is greater than the Consumer Price Index.

This section authorizes to be appropriated $81,270,000 for fiscal year 1991, $85,335,000 for fiscal year 1992, $89,600,175 for fiscal year 1993, and $94,080,190 for fiscal year 1994.

TITLE III—PROTECTION AND ADVOCACY

Section 13 amends Section 142 and clarifies the conditions under which protection and advocacy systems have access to records in those extraordinary situations when there is reason to believe that the health or safety of an individual with developmental disabilities is in serious or immediate jeopardy, and the legal guardian, conservator, or other legal representatives have been contact, offered assistance, but have failed or refused to act on behalf of the person.

This section also clarifies the term "records"; clarifies the process by which the Governor may redesignate the State agency implementing the Protection and Advocacy System; and who may be appointed to a governing board. This section also reiterates that Protection and Advocacy Systems may bring suit on behalf of persons with developmental disabilities against a State or agencies or instrumentalities of a State, as has been their longstanding practice.

This section clarifies that any amounts paid to the Protection and Advocacy System as a result of court judgements must be used to further the purposes of the System as set out by this Act, and that a system may receive allotments under this Act in direct payment unless they delegate the payment to occur otherwise.

Section 14 authorizes to be appropriated $27,000,000 for fiscal year 1991, $28,350,000 for fiscal year 1992, $29,770,000 for fiscal year 1993, and $31,258,500 for fiscal year 1994.

TITLE IV—UNIVERSITY AFFILIATED PROGRAMS

Section 15 amends Section 152 and retains the Secretary's authority to make grants to UAPs receiving core funding for the purpose of providing service-related training and conducting applied research.

This section retains the training grant initiative as a core training award. Grants in the amount of $90,000 are to be awarded for three years, if sufficient funds are available, and must be renewed on a competitive basis. If sufficient funds are available the Secretary has the discretion to award grants up to $150,000 if applications are of sufficient scope and quality, and address issues of National significance.

Priority areas in early intervention, aging, and community based service programs are retained. New priority areas are created in assistive technology and positive behavior management. An additional priority area is created which allows a UAP, in consultation with the Planning Council and the citizen advisory group, to develop a priority area that meets a need specific to the State they serve. UAPs may apply for training grants that address more than one priority area. UAPs who apply for grants under this section must establish a consumer advisory group.

This section also creates a peer review process as a means of monitoring training grants and assuring quality programs. Criteria

for peer reviews is also included. This section provides for the Secretary to utilize funds under this Section, which are not awarded to applicants who submit applications of insufficient quality as determined by peer review, to make awards to other UAPs for the purposes set out in this section, not to exceed $150,000.

Section 16 amends Section 153 and provides for the continued expansion of UAP programs to all states. Applicants from states who are not served by a UAP will be given first priority. However, in the event applications of sufficient quality are not received from states who are unserved by a UAP, the Secretary may consider applications from states that are served by a UAP or satellite center which is not able to serve particular geographic regions of the State, if such applications demonstrate a need.

Section 17 authorizes to be appropriated for core funding $11,400,000 for fiscal year 1991, $12,390,000 for fiscal year 1992, $13,430,000 for fiscal year 1993, and $14,310,000 for fiscal year 1994. The bill also includes a separate line item for training grants to UAPs and satellites that authorizes to be appropriated $7,000,000 for fiscal year 1991, $8,652,000 for fiscal year 1992, $10,386,000 for fiscal year 1993, and $12,050,000 for fiscal year 1994.

TITLE V—PROJECTS OF NATIONAL SIGNIFICANCE

Section 18 amends Section 161 to include in the purpose "and to support the development of National and State policy which enhances the independence, productivity, and integration of persons with developmental disabilities through data collection and analysis, technical assistance to program components, technical assistance for the development of information and referral systems, educating policy makers, Federal interagency initiatives, and the enhancement of minority participation in public and private sector initiatives in developmental disabilities."

Section 19 amends Section 162 to include projects which "improve supportive living and quality of life opportunities which enhance recreation, leisure and fitness". This section also modifies the term "technical assistance and demonstration projects" to "technical assistance" in recognition that technical assistance has been successfully demonstrated.

Section 20 authorizes to be appropriated $3,900,000 for fiscal year 1991, $4,095,525 for fiscal year 1992, $4,299,750 for fiscal year 1993, and $4,514,800 for fiscal year 1994. This section also specifies that at least 8% of this authorization, and no less than $300,000 shall be used to provide technical assistance, training, and evaluation which expand or improve the advocacy functions of the State Planning Council, the functions performed by the University Affiliated Programs and satellite centers, and protection and advocacy services relating to the State Protection and Advocacy System.

VIII. Changes in Existing Law

In compliance with rule XXVI paragraph 12 of the Standing Rules of the Senate, the following provides a print of the statute or the part of the section thereof to be amended or replaced (existing law proposed to be omitted is enclosed in black brackets, new

matter is printed in italic, existing law in which no change is proposed is shown in roman):

* * * * * * *

FINDINGS AND PURPOSES

SEC. 101. (a) The Congress finds that—

(1) [there are more than two] *in 1990 there are more than three* million persons with developmental disabilities in the United States;

* * * * * * *

(7) a substantial portion of persons with developmental disabilities remain unserved or underserved;

[(7)] *(8)* public and private employers tend to be unaware of the capability of persons with developmental disabilities to be engaged in competitive work in integrated settings; and

[(8)] *(9)* it is in the national interest to offer persons with developmental disabilities the opportunity, to the maximum extent feasible, to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens.

(b) The purposes of this title are—

(1) * * *

* * * * * * *

(2) to enhance the role of the family in assisting persons with developmental disabilities to achieve their maximum potential; [and]

(3) to provide interdisciplinary training and technical assistance to professionals, paraprofessionals, family members, and individuals with developmental disabilities;

(4) to advocate for public policy change and community acceptance of all people with developmental disabilities and their families so that such persons receive the services, supports and other assistance and opportunities necessary to enable such persons to achieve their maximum potential through increased independence, productivity and integration into the community;

(5) to promote the inclusion of all persons with developmental disabilities, including persons with the most severe disabilities, in community life;

(6) to promote the interdependent activity of all persons with developmental disabilities, including persons with the most severe disabilities;

(7) to recognize the contribution of all persons with developmental disabilities as such persons share their talents at home, school, and work, and in recreation and leisure time; and

[(3)] *(8)* to make grants to support a system in each State to protect the legal and human rights of persons with developmental disabilities.

DEFINITIONS

SEC. 102 * * *

* * * * * * *

(5) The term "developmental disability" means a severe, chronic disability of a person *5 years of age or older* which—

* * * * * * *

(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated[.]; *except that such term, when applied to infants and young children, means an individual from birth to age 5, inclusive, with a substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.*

* * * * * * *

(8) The term "integration" means—

(A) the—

(i) use by persons with developmental disabilities of the same community resources that are used by and available to other citizens, [and]

(ii) participation by persons with developmental disabilities in the same community activities *and integrated employment* in which [nondisabled citizens] *citizens without disabilities* participate,

(iii) use of the same community resources by persons with developmental disabilities living, learning, working, and enjoying life in regular contact with citizens without disabilities, and

(iv) development of friendships and relationships with persons without disabilities,

together with regular contact with [nondisabled citizens,] *citizens without disabilities,* and

(B) the residence by persons with developmental disabilities in home [or in home-like settings] which are in proximity to community resources, together with regular contact with [nondisabled citizens] *citizens without disabilities* in their communities.

(9) The term "priority area activities" includes, with respect to Federal priority areas or a State priority area—

* * * * * * *

(B) the—

* * * * * * *

(iv) presentation of information, [models,] *approaches, strategies,* findings, conclusions, and recommendations to *Federal, State and local* policymakers,

in order to enhance opportunities for persons with developmental disabilities, including the enhancement of a system for providing or making available specialized services or special adap-

tations of generic services for persons with developmental disabilities and the families of such persons;

* * * * * * *

(10) The term "Federal priority areas" means community living activities, employment activities, child development activities, and [case management] *system coordination and community education* activities.

* * * * * * *

(12) The term "community living activities" means such priority are activities as will assist persons with developmental disabilities in developing or maintaining suitable residential arrangements and supports in the community (including nonfinancial supports [and family support services], *individual, family and community supports*).

* * * * * * *

[(21) The term "family support services" means services designed to—

[(A) strengthen the family's role as primary caregivers;

[(B) prevent inappropriate out-of-the-home placement and maintain family unity; and

[(C) reunite families with members who have been placed out of the home.

Such term includes respite care, personal care, parent training and counseling, support for elderly parents, and other individualized services.]

(21) The term "protection and advocacy system" means a protection and advocacy system established in accordance with section 142.

(22) The term "assistive technology" means the systematic application of technology, engineering methodologies, or scientific principles to meet the needs of, and address the barriers confronted by, persons with developmental disabilities in areas including education, employment, supported employment, transportation, and independent living and other community living arrangements. *Such term includes assistive technology devices and assistive technology service.*

* * * * * * *

(24) The term "family support service" means services, supports, and other assistance provided to families with members with development disabilities, that are designed to—

(A) strengthen the family's role as primary caregiver;

(B) prevent inappropriate out of the home placement and maintain family unity; and

(C) reunite families with members who have been placed out of the home. Such term includes respite care, assistive technology, personal assistance, parent training and counseling, support for elderly parents, vehicular and home modifications, and assistance with extraordinary expenses associated with the need of the person with a developmental disability.

(25) The term "individual supports" means services, supports, and other assistance that enable persons with developmental disabilities

to be independent, productive, and integrated into their communities, and that are designed to—

(A) enable the person to control his or her environment, permitting the most independent life possible,

(B) prevent placement into a more restrictive living arrangement than is necessary, and

(C) enable the person to live, learn, work, and enjoy life in the community.

Such term includes personal assistance services, assistive technology, vehicular and home modifications, support at work, and transportation.

(26) The term "community supports" means providing activities, services, supports, and other assistance to persons with developmental disabilities, and the families and communities of such persons, that are designed to—

(A) assist neighborhoods and communities to be more responsive to the needs of persons with developmental disabilities and their families,

(B) develop local networks which can provide informal support, and

(C) make communities accessible and enable communities to offer their resources and opportunities to persons with developmental disabilities and their families.

Such term includes community education, personal assistance services, vehicular and home modifications, support at work, and transportation.

(27) The term "system coordination and community education activities" means activities that—

(A) eliminate barriers to access and eligibility for services, supports, and other assistance,

(B) enhance systems design and integration including the encouragement of the creation of local case management and information and referral statewide systems, and

(C) enhance citizen participation and involvement.

(28) The term "assistive technology device" means any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improvement functional capabilities of a person with a developmental disability.

(29) The term "assistive technology service" means any service that directly assist a person with a developmental disability in the selection, acquisition, or use of an assistive technology device. Such term includes—

(A) the evaluation of the needs of a person with a developmental disability, including a functional evaluation of the person in the person's customary environment;

(B) purchasing, leasing or otherwise providing for the acquisition of assistive technology devices by a person with a developmental disability;

(C) selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing or replacing assistive technology devices;

(D) coordinating and using other therapies, interventions, or services with assistive technology devices, such as therapies,

interventions or services associated with existing education and rehabilitation plans and programs;

(E) training or technical assistance for a person with developmental disabilities, or, where appropriate, the family of a person with a developmental disability; and

(F) training or technical assistance for professionals (including persons providing education and rehabilitation services), employers, or other persons who provide services to, employ, or are otherwise substantially involved in the major life functions of a person with developmental disability.

(30) The term "prevention" means activities which address the causes of developmental disabilities and the exacerbation of functional limitations, such as activities which—

(A) eliminate or reduce the factors which cause or predispose persons to developmental disabilities or which increase the prevalence of developmental disabilities;

(B) increase the early identification of existing problems to eliminate circumstances that create or increase functional limitations; and

(C) mitigate against the effects of developmental disabilities throughout the lifespan.

FEDERAL SHARE

SEC. 103. (a) The Federal share of all projects in a State supported by an allotment to the State unde part B may not exceed 75 percent of the aggregate necessary costs of all such projects, as determined by the Secretary, except that in the case of projects [located] *whose activities or products target people who live* in urban or rural poverty areas, the Federal share of all such projects may not exceed 90 percent of the aggregate necessary costs of such projects, as determined by the Secretary.

(b) The Federal share of any project to be provided through grants under part D may not exceed 75 percent of the necessary cost of such project, as determined by the Secretary, except that if the project [is located] *activities or products target people who live* in an urban or rural poverty area, the Federal share may not exceed 90 percent of the project's necessary costs as so determined.

(c) The non-Federal share of the cost of any project assisted by a grant or allotment under *part B of* this title may be provided in kind.

* * * * * * *

REPORTS

SEC. 107. (a) * * *

* * * * * * *

(1) * * *

* * * * * * *

(4) a description of the State Planning Council's response to significant actions taken by the State with respect to [each annual survey report and plan of corrections for cited deficiencies prepared pursuant to section 1902(a)(31)(B) of the Social

Security Act with respect to any intermediate care facility for the mentally retarded in such State;] *any intermediate care facility for the mentally retarded in such State, and with respect to each annual survey report prepared pursuant to section 1902(a)(31)(C) of the Social Security Act and each correction or reduction plan prepared pursuant to section 1922 of such Act;* and

(5) a description of the progress made in the State in, and any identifiable trends concerning, the setting of priorities for, policy reform concerning, [and advocacy for,] *advocacy for, and other actions on behalf of and with* persons with developmental disabilities which are attributable to physical impairment, mental impairment, or a combination of physical and mental impairments, *particularly unserved and underserved groups,* including any other subpopulation of persons with developmental disabilities (including minorities) [that the State Planning Council may identify under sections 122(b)(3) and 122(f).] *and a summary of actions taken to improve access to and services for unserved and underserved groups that the State Planning Council may have identified.*

* * * * * * *

(c)(1) By [April] *July* 1 of each year the Secretary shall prepare and transmit to the President, and the Congress, and the National Council on [the Handicapped] *Disability* a report which describes—

(A) * * *

* * * * * * *

(C) the progress made by States in, and any identifiable trends concerning, the setting of priorities for, policy reform concerning, [and advocacy for,] *advocacy for, and other actions on behalf of,* persons with developmental disabilities attributable to physical impairment, mental impairment, or a combination of physical and mental impairment, *particularly unserved or underserved groups,* including any other subpopulation of persons with developmental disabilities (including minorities) that the State Planning Council [may identify] *has identified* under sections 122(b)(3) and 122(f), *and a summary of actions taken to improve access to services for such groups;*

* * * * * * *

RESPONSIBILITIES OF THE SECRETARY

SEC. 108. (a) * * *

* * * * * * *

(b) Within ninety days after the date of enactment of the Developmental Disabilities Act of 1984, the Secretary of Health and Human Services and the Secretary of Education shall establish an interagency committee composed of representatives of the Administration for Developmental Disabilities, *the Administration on Children, Youth and Families, the Administration on Aging, and the Health Resources and Services Administration* of the Department of Health and Human Services, the Office of Special Education and

Rehabilitative Services of the Department of Education, the Department of Labor, and such other Federal departments and agencies as the Secretary of Health and Human Services and the Secretary of Education consider appropriate. Such interagency committee shall meet regularly to coordinate and plan activities conducted by Federal departments and agencies for persons with developmental disabilities. *Such interagency committee shall provide to Congress within 90 days of the implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 1990 and annually thereafter an agenda and description of activities for addressing issues and topics of national concern, based on findings from the report conducted pursuant to section 122(f). The agenda shall designate the issues to be addressed for the coming year and the action plan shall specify the role, activities, timeliness and evaluation criteria of each participating agency regarding each issue. All interagency committee meeting dates and agendas shall be made available to the public in a timely manner.*

* * * * * * *

EMPLOYMENT OF HANDICAPPED INDIVIDUALS

SEC. 109. As a condition of providing assistance under this title, the Secretary shall require that each recipient of such assistance take affirmative action to employ and advance in employment qualified handicapped individuals on the same terms and conditions required with respect to the employment of such individuals by the provisions of the Rehabilitation Act of [1972] *1973* which govern employment (1) by State rehabilitation agencies and rehabilitation facilities, and (2) under Federal contracts and subcontracts.

RIGHTS OF THE DEVELOPMENTALLY DISABLED

SEC. 110. * * *

* * * * * * *

(4) All programs for persons with developmental disabilities should meet standards which are designed to assure the most favorable possible outcome for those served, and—

(A) in the case of residential programs serving persons in need of comprehensive health-related, habilitative, or rehabilitative services, which are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded promulgated in regulations of the Secretary on [January 17, 1974 (39 Fed. Reg. pt. II),] *October 3, 1988*, as appropriate when taking into account the size of the institutions and the service delivery arrangements of the facilities of the programs;

* * * * * * *

PART B—FEDERAL ASSISTANCE FOR PLANNING PRIORITY AREA ACTIVITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

PURPOSE

SEC. 121.

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STATE PLANS

SEC. 122. (a) * * *

* * * * * * *

(B) The plan must designate the State agency which shall administer or supervise the administeration of the State plan (hereafter in this part referred to as the "designated State agency"). *Such designated State agency shall, on behalf of the State receive and account for funds, and at the direction of the State Planning Council, disburse funds pursuant to part B, and shall provide administrative support services to the State Planning Council.* Except as provided in subsection (e), the designated State agency may be—

* * * * * * *

(2) The plan must—

* * * * * * *

(C) describe (and provide for the review annually and revision of the description not less often than once every three years) (i) the extent and scope of services, *supports and other assistance* being provided, or to be provided, to persons with developmental disabilities under such other State plans or, *or policies affecting,* federally assisted State programs that the State conducts and in which persons with developmental disabilities are *or may be* eligible to participate, including programs relating to education, job training, vocational rehabilitation, public assistance, medical assistance, social services, *child welfare,* maternal and child health, aging, programs for children with special health care needs, housing, *transportation, technology,* comprehensive health and mental health, and such [other plans] *other programs* as the Secretary may specify, [and (ii)];

(ii) the extent to which such federally assisted State programs develop and pursue interagency initiatives aimed at improving and enhancing services for persons with developmental disabilities, and (iii) how funds allotted to the State in accordance with section 125 will be used to complement and augment rather than duplicate or replace services for persons with developmental disabilities *and their families* who are eligible for Federal assistance under such other State programs;

(D) assess, and if appropriate, update the findings of the report conducted pursuant to subsection (f), and report on any progress achieved concerning issues identified in the report conducted pursuant to such subsection in the previous fiscal year;

[(D)] *(E)* for each fiscal year, assess and describe the extent and scope of the Federal and State priority areas which are ad-

dressed or which will be addressed under the plan in the fiscal year; and

[(E)] *(F)* establish a method for the periodic evaluation of the plan's effectiveness in meeting the objectives described in subparagraph (A).

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(5)(A) * * *

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(B) * * *

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(i) * * *

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(iii) an analysis of the special and common needs of all subpopulations of persons with developmental disabilities;

(iv) consideration of the report conducted pursuant to subsection (f);

[(iii)] *(v)* an analysis of services, assistive technology, or knowledge which may be unavailable to assist persons with developmental disabilities;

[(iv)] *(vi)* an analysis of existing and projected fiscal resources;

[(v)] *(vii)* an analysis of any other issues identified by the State Planning Council; and

[(vi)] *(viii)* the formulation of objectives in both policy reform and service demonstration to address the issues described in clauses (i) through (v) for all subpopulations of persons with developmental disabilities which may be identified by the State Planning Council.

* * * * * * *

(D)(i) The plan must provide that not less than 65 percent of the amount available to the State under section 125 will be expended for activities in the Federal priority area of employment activities, and, at the discretion of the State, activities in any or all of the three other Federal priority areas and a State priority area, the conduct of the analyses specified in clauses (i) through (v) of subparagraph (B), [and] the implementation of paragraph (3) and subsection (f)[.], *and activities which address the implementation of recommendations made in the report described in subsection (f), including recommendations which address unserved and underserved populations.*

* * * * * * *

(d)(1) At the request of any State, a portion of any allotment or allotments of such State under this part for any fiscal year shall be available to pay one-half (or such smaller share as the State may request) of the expenditures found necessary by the Secretary for the proper and efficient [administration of the State plan approved under this section] *exercise of the functions of the State designated agency*; except that not more than 5 per centum of the total of the allotments of such State for any fiscal year, or $50,000, whichever is less, shall be available for the total expenditures for

such purpose by [all of the State agencies designated under subsection (b)(1)(B) for the administration or supervision of the administration of the State plan] *the State agency designated under subsection (b)(1)(B).* Payments under this paragraph may be made in advance or by way of reimbursement, and in such installments, as the Secretary may determine. *State contributions pursuant to this paragraph may be counted as part of such State's non-Federal share of allotments under this part.*

* * * * * * *

(e)(1) * * *

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(5) After October 1, 1990, the Planning Council may issue a request for a review of the designation of the designated State agency by the Governor.

(f)(1) * * *

* * * * * * *

(4) Each State Planning Council shall utilize the information developed pursuant to paragraphs (1), (2), and (3) in developing the State plan.

[(4) By January 1, 1990, each State Planning Council shall prepare and transmit to the Governor of the State and the legislature of the State a final written report concerning the review and analyses conducted under paragraphs (1) and (2). The report shall contain recommendations by the State Planning Cuoncil concerning—

[(A) the most appropriate agency or agencies of the State to be designated as responsible for the provision and coordination of services for persons with developmental disabilities who are traditionally underserved, such a persons with developmental disabilities attributable to physical impairment, persons with developmental disabilities attributable to dual mental impairments, and persons with developmental disabilities attributable to a combination of physical and mental impairments, and such other subpopulations of persons with developmental disabilities (including minorities) as the State Planning Council may identify; and

[(B) the steps to be taken to include the data and recommendations obtained through the conduct of the reviews and analyses under paragraphs (1) and (2) in the State Planning Council's ongoing advocacy, public policy, and model service demonstration activities.

[(5) By January 5, 1990, the Governor of each State shall submit to the Secretary a copy of the report required by paragraph (4). By April 1, 1990, the Secretary shall transmit a summary of such reports to the appropriate committees of the Congress.]

* * * * * * *

STATE PLANNING COUNCILS

SEC. 124. (a) Each State which receives assistance under this part shall establish a State Planning Council [which will] *to* serve as

an advocate for all persons with developmental disabilities[.] *by carrying out priority over activities.*

* * * * * * *

(c)(1) Each State Planning Council [may] *shall* prepare and approve a budget using amounts paid to the State under this part to [hire] *fund all activities under this part (except administrative costs) and to hire* such staff and obtain the services of such professional, technical, and clerical personnel consistent with State law as the State Planning Council determines to be necessary to carry out its functions under this part.

(2) Each State Planning Council shall, consistent with State law, hire a Director of the State Planning Council who shall be supervised and evaluated by the State Planning Council and who shall hire and supervise the staff of the State Planning Council.

[(2)] *(3)* The staff and other personnel of a State Planning Council, while working for the State Planning Council, shall be responsible solely for assisting the State Planning Council in carrying out its duties under this part and shall not be assigned duties by the designated State agency or any other agency or office of the State.

(d) Each State Planning Council shall—

(1) develop [jointly with] *and submit after consultation with* the State agency designated under section 122(b)(1)(B) the State plan required by this part including the specifications of Federal and State priority area activities under section 122(b)(5)(D)(i);

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SEC. 125. State allotments.

(a) * * *

* * * * * * *

[(3)(A) Except as provided in paragraph (4), for any fiscal year the allotment under paragraph (1)—

[(i) to each of the American Samoa, Guam, the Virgin Islands, the Commonwealth of the Northern Mariana Islands, or the Trust Territory of the Pacific Islands may not be less than $160,000, and

[(ii) to any other State may not be less than the greater of $300,000, or the amount of the allotment (determined without regard to subsection (d) of this section) received by the State for the fiscal year ending September 30, 1984.

[(B) Notwithstanding subparagraph (A), if the aggregate of the amounts to be allotted to each State pursuant to subparagraph (A) in any fiscal year exceeds the total amount appropriated under section 6030 of this title for such fiscal year, the amount to be allotted to a State for such fiscal year shall be an amount which bears the same ratio to the amount which is to be allotted to the State pursuant to such subparagraph as the total amount appropriated under section 6030 of this title for such fiscal year bears to the total of the amount required to be appropriated under such section for allotments to provide each State with the allotment required by such subparagraph.

[(4) In any case in which amounts appropriated under section 6030 of this title for a fiscal year exceed $60,000,000, the allotment under paragraph (1) for such fiscal year—

[(A) to each of American Samoa, Guam, the Virgin Islands, the Commonwealth of the Northern Mariana Islands, or the Trust Territory of the Pacific Islands may not be less than $200,000; and

[(B) to each of the several States, Puerto Rico, or the District of Columbia, may not be less than $350,000.

[(5) In determining, for purposes of paragraph (1)(B), the extent of need in any State for services for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services described, pursuant to section 6022(b)(2)(C) of this title, in the State plan of the State.

[(6) In any case in which the total amount appropriated under section 6030 of this title for a fiscal year exceeds the total amount appropriated under such section for the preceding fiscal year by a percentage greater than the most recent percentage change in the Consumer Price Index published by the Secretary of Labor under section 720(c)(1) of Title 29, the Secretary may increase each of the minimum allotments of such minimum allotment (including any increases in such minimum allotment under this paragraph for prior fiscal years) as the amount which is equal to the difference between—

[(A) the total amount appropriated under section 6030 of this title for the fiscal year for which the increase in minimum allotment is being made, minus

[(B) the total amount appropriated under section 6030 of this title for the immediately preceding fiscal year,

bears to the total amount appropriated under section 6030 of this title for such preceding fiscal year.]

(3)(A) Except as provided in paragraph (4), for any fiscal year the allotment under paragraph (1)—

(i) to each of American Samoa, Guam, the Virgin Islands, the Commonwealth of the Northern Mariana Islands, the Republic of the Marshall Islands, the Federated States of Micronesia, or the Republic of Palau may not be less than $200,000; and

(ii) to any other State may not be less than the greater $350,000 or the amount of the allotment (determined without regard to subsection (d)) received by the State for the fiscal year ending September 30, 1990.

(B) Notwithstanding subparagraph (A), if the aggregate of the amounts to be allotted to each State pursuant to subparagraph (A) in any fiscal year exceeds the total amount appropriated under section 130 for such fiscal year, the amount to be allotted to a State for such fiscal year shall be an amount which bears the same ratio to the amount which is to be allotted to the State pursuant to such subparagraph as the total amount appropriated under section 130 for such fiscal years bears to the total of the amount required to be appropriated under such section for allotments to provide each State with the allotment required by such subparagraph.

(4) In any case in which amounts appropriated under section 130 for a fiscal year exceeds $65,000,000, the allotment under paragraph (1) for such fiscal year—

(A) to each of American Samoa, Guam, the Virgin Islands, the Commonwealth of the Northern Mariana Islands, the Republic of the Marshall Islands, the Federated States of Micronesia, or the Republic of Palau may not be less than $210,000; and

(B) to each of the several States, Puerto Rico or the District of Columbia may not be less than $400,000.

(5) In determining, for purposes of paragraph (1)(B), the extent of need in any State for services for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services described, pursuant to section 122(b)(2)(C), in the State plan of the State.

(6) In any case in which the total amount appropriated under section 130 for a fiscal year exceeds the total amount appropriated under such section for the preceding fiscal year by a percentage greater than the most recent percentage change in the Consumer Price Index published by the Secretary of Labor under section 100(c)(1) of the Rehabilitation Act of 1973, the Secretary shall increase each of the minimum allotments under paragraphs (3) and (4) by an amount which bears the same ratio to the amount of such minimum allotment (including any increases in such minimum allotment under this paragraph for prior fiscal years) as the amount which is equal to the difference between—

(A) the total amount appropriated under section 130 for the fiscal year for which the increase in minimum allotment is being made, minus

(B) the total amount appropriated under section 130 for the immediately preceding fiscal year,

bears to the total amount appropriated under section 130 for such preceding fiscal year.

* * * * * * *

AUTHORIZATION OF APPROPRIATIONS

SEC. 130. For allotments under section 125, there are authorized to be appropriated [$62,200,000 for fiscal year 1988, $69,900,000 for fiscal year 1989, and $77,400,000 for fiscal year 1990.] *$81,270,000 for fiscal year 1991, $85,335,000 for fiscal year 1992, $89,600,175 for fiscal year 1993, and $94,080,190 for fiscal year 1994.*

* * * * * * *

SYSTEM REQUIRED

SEC. 142. (a) * * *

* * * * * * *

(1) the State must have in effect a system to protect and advocate the rights of persons with developmental disabilities;

(2) such system must—

(A) * * *

* * * * * * *

(F) be independent of any agency which provides treatment, services, or habilitation to persons with developmental disabilities; [and]

(G) have access to all records of—

(i) any person with developmental disabilities who is a client of the system if such person, or the legal guardian, conservator, or other legal representative of such person, has authorized the system to have such access; [and]

(ii) any person with developmental disabilities—

(I) * * *

* * * * * * *

(iii) any person with a developmental disability who has a legal guardian, conservator, or other legal representative with respect to whom a complaint has been received by the system or with respect to whom there is probable cause to believe the health or safety of the individual is in serious and immediate jeopardy whenever—

(I) such representatives have been contacted by such system upon receipt of the name and address of such representatives;

(II) such system has offered assistance to such representatives to resolve the situation; and

(III) such representatives have declined to act on behalf of the person; and

(iv) any person with a developmental disability who resides in a public facility when as a result of monitoring visits the system has reason to believe that the person may be subject to abuse or neglect;

* * * * * * *

(5) the State must provide assurances satisfactory to the Secretary that the agency implementing the system will not be redesignated unless there is good cause for the redesignation and [unless notice has been given of the intention to make such redesignation to persons with developmental disabilities or their representatives.] *unless—*

(A) notice has been given of the intention to make such redesignation to the agency that is serving as the system including the good cause for such redesignation and the agency has been given an opportunity to respond to the assertion that good cause has been shown;

(B) timely notice and opportunity for public comment in an accessible format has been given to persons with developmental disabilities or their representatives; and

(C) the system has the opportunity to appeal to the Secretary that the redesignation was not for good cause.

(b) Allotments to States; percentage limitation

(1) * * *

* * * * * * *

(2) In any case in which the total amount appropriated under section 6043 of this title for a fiscal year exceeds the total amount appropriated under such section for the preceding fiscal year by a percentage greater than the most recent percentage change in the Consumer Price Index published by the Secretary of Labor under section 720(c)(1) of Title 29, the Secretary [may] *shall* increase each of the minimum allotments under subparagraphs (A) and (B) of paragraph (1) by an amount which bears the same ratio to the amount of such minimum allotment (including any increases in such minimum allotment under this paragraph for prior fiscal years) as the amount which is equal to the difference between—

* * * * * * *

(c) * * *

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(d) In States in which the system is organized as a private nonprofit entity with a multimember governing board, such governing board shall be selected according to the policies and procedures of the system. Such governing board shall be composed of—

(1) members (to be selected not later than 60 days following a vacancy) who broadly represent or are knowledgeable about the needs of the clients served by the system; and

(2) in the case of a governing authority organized as a private nonprofit entity, members who broadly represent, or are knowledgeable about, the needs of the clients served by the system.

(e) As used in this section the term "records" includes reports prepared or received by any staff of a facility rendering care or treatment, or reports prepared by an agency or staff person charged with investigating reports of incidents of abuse or neglect, injury or death occurring at such facility that describes incidents of abuse, neglect, injury or death occurring at such facility and the steps taken to investigate such incidents, and discharge planning records.

(f) If the laws of a State prohibit a system from obtaining access to records of persons with developmental disabilities the provisions of subparagraph (A) of paragraph (2) of subsection (a) shall not apply to such system before—

(1) the date such system is no longer subject to such prohibition; or

(2) the expiration of the 1-year period beginning on the date of enactment of this Act, whichever occurs first.

(g)(1) Nothing in this Act shall preclude the systems described under this section from bringing a suit on behalf of persons with developmental disabilities against a State, or agencies or instrumentalities of a State.

(2) Amounts received pursuant to paragraph (1) through court judgments and used by the system are limited to furthering the purpose of this part and shall not be used to augment payments to legal contractors or to award personal bonuses.

(h) Notwithstanding any other provision of law, the Secretary shall pay directly to any system which complies with the provisions

of this section the amount of such system's allotment under this section, unless the system delegates otherwise.

AUTHORIZATION OF APPROPRIATIONS

SEC. 143. For allotments under section 142, there are authorized to be appropriated [$20,000,000 for fiscal year 1988, $22,000,000 for fiscal year 1989, and $24,200,000 for fiscal year 1990.] *$27,000,000 for fiscal year 1991, $28,350,000 for fiscal year 1992, $29,770,000 for fiscal year 1993, and $31,258,000 for fiscal year 1994.*

* * * * * * *

GRANT AUTHORITY

SEC. 152. (a) * * *

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(b)(1)(A) From amounts appropriated under section 154(b), the Secretary shall make grants of [sufficient size and scope] to university affiliated programs receiving grants under subsection (a) to support training projects to train personnel to address the needs of persons with developmental disabilities in areas of emerging national significance, particularly projects to train personnel in the areas of early intervention programs (as described in paragraph (2)), programs for elderly persons with developmental disabilities (as described in paragraph (3)), [and] community-based service programs (as described in paragraph (4))[.], *positive behavior management programs (as described in paragraph (5)), assistive technology programs (as described in paragraph (6)) and programs in other areas of national significance as determined by the university affiliated program, in consultation with the State Planning Council (as described in paragraph (7)).*

[(B) The Secretary shall make determinations with respect to grants under this subsection based on information relating to present and projected needs for the training of personnel based on identified State, regional, or national shortages of personnel, the capacity of the university affiliated programs to train personnel, and such other information as may be determined necessary and appropriate by the Secretary.]

(B)(i) Grants awarded under this subsection shall be in the amount of $90,000.

(ii) The Secretary may waive the provisions of clause (i) and award grants under this subsection in an amount which does not exceed $150,000, if the Secretary determines that such grants are of such sufficient scope and quality so as to address issues of national significance as identified in the report conducted pursuant to section 122(f).

(C)(i) Grants under this section shall be awarded on a competitive basis. Grants awarded under this section shall be awarded for a period of 4 years and are renewable.

(D) The Secretary shall require appropriate technical and qualitative peer review of applications for assistance under this subsection by peer review groups as established under section 153(e)(4) using the following criteria:

(i) The university affiliated program shall present evidence that core training assisted by funds awarded under this section is—

(I) competency and value based;

(II) designed to facilitate independence, productivity and integration for persons with developmental disabilities; and

(III) evaluated utilizing state of the art evaluation techniques in the programmatic areas selected.

(ii) Core training shall—

(I) represent state-of-art techniques in areas of critical shortage of personnel which are identified through consultation with the citizens advisory group designated pursuant to subsection (f) and the State Planning Council;

(II) be conducted in consultation with the citizens advisory group designated under subsection (f) and the State developmental disabilities planning council;

(III) be integrated into the appropriate university affilated program and university curriculum;

(IV) be integrated with relevant State agencies in order to achieve an impact on state-wide personnel and service needs;

(V) to the extent practicable, be conducted in environments where services are actually delivered; and

(VI) to the extent possible, be interdisciplinary in nature.

(E)(i) Grants awarded under this subsection shall not be used for administrative expenses.

(ii) Grants awarded under this subsection shall not be used to carry out the provisions of subsection (a).

[(C)] *(F)* Grants under this subsection may be used by university affiliated programs to (i) assist in paying the costs of courses of training or study for personnel to provide services for persons with developmental disabilities and (ii) establish fellowships or traineeships providing such stipends and allowances as may be determined by the Secretary.

* * * * * * *

(4) * * *

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(5) Grants awarded under this subsection for training projects with respect to positive behavior management intervention programs shall be for the purpose of assisting university affiliated programs in providing training to families, foster parents, paraprofessionals, other appropriate community-based staff, and institutional staff, including health care staff and behavioral specialists, who provide or will provide, positive behavior management interventions for persons with developmental disabilities. Such training interventions shall include—

(A) ethical principles and standards;

(B) appropriate assessment of the origin of behavior problems including antecedent behaviors, the environment, medical problems (including seizure disorders), other neurological problems, or medication side effects;

(C) the development of a positive behavior management plan;

(D) the use of positive reinforcements appropriate to the developmental level of the person;

(E) the use of emergency procedures; and

(F) the administration of appropriate psychotropic drugs including drugs which the person may be taking for other conditions such as seizure disorders.

(6) Grants under this subsection for training projects with respect to assistive technology programs shall be for the purpose of assisting university affiliated programs in providing training to allied health personnel and other personnel who provide or will provide, assistive technology services to persons with developmental disabilities. Such projects may provide training and technical assistance to improve the quality of service delivery in community-based, nonprofit consumer and provider service programs for persons with developmental disabilities and may include stipends and tuition assistance from such organizations. Such projects shall be coordinated with State technology coordinating councils wherever such councils exist.

(7) Grants under this subsection for training projects with respect to programs in other areas of national significance shall be for the purpose of training personnel in an area of special concern to the university affiliated program, and shall be developed in consultation with the State Planning Council.

* * * * * * *

(f) The Secretary shall only make grants under this section to university affiliated programs which establish a consumer advisory committee comprised of consumers, family members, representatives of State protection and advocacy systems, developmental disabilities councils (including State service agency directors), local agencies, and private nonprofit groups concerned with providing services for persons with developmental disabilities.

(g) A university affiliated program shall not be eligible to receive funds for training projects pursuant to this section unless—

(1) such program has operated for at least 1 year; or

(2) the Secretary determines that such project has demonstrated the capacity to develop an effective training program during the first year such program is operated.

APPLICATIONS

SEC. 153. (a) * * *

* * * * * * *

(3)(A) For purposes of making grants under section 152(a), the Secretary shall consider applications for grants for four university affiliated applications or satellite centers for each of the fiscal years [1988, 1989, and 1990] *1991, 1992, and 1993* which are in addition to the total number of university affiliated programs and satellite centers receiving grants under such section for the preceding fiscal year. *The Secretary shall solicit and may approve applications pursuant to this paragraph which encompass multiple universities within the same State university system or two or more universities which are otherwise unrelated.*

* * * * * * *

(B) Such programs and centers shall, to the extent feasible, be geographically distributed for the purpose of serving States that are unserved by university affiliated programs and satellite centers under this part on the date of enactment of the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987. *If an insufficient number of quality applications, as determined by a peer review process, from such unserved States have not been recieved in any fiscal year, the Secretary may consider applications for such fiscal year from States that are served by a university affiliated program or satellite center which is not able to serve particular geographic regions of the State, only if such applications demonstrate a need for additional training within the State and an exemplary service capacity to serve individuals within the State.*

* * * * * * *

(e)(1) The Secretary shall [by regulation] require appropriate technical and qualitative peer review of applications for assistance under this part by peer review groups established under paragraph (4)[.], *including on-site visits or inspections as necessary. Such peer review shall be coordinated, as appropriate, with the peer review described in section 152(b)(1)(D).*

* * * * * * *

AUTHORIZATION OF APPROPRIATIONS

[SEC. 154. (a) For the purpose of grants under subsections (a), (d), and (e) of section 152, there are authorized to be appropriated $9,400,000 for fiscal year 1988, $10,200,000 for fiscal year 1989, and $11,000,000 for fiscal year 1990. Amounts appropriated under this section for a fiscal year shall remain available for obligation and expenditure until the end of the succeeding fiscal year.

[(b) For the purpose of grants under section 152(b) and 152(c), there are authorized to be appropriated $4,500,000 for fiscal year 1988, $5,000,000 for fiscal year 1989, and $5,500,000 for fiscal year 1990.

[(c) The Secretary may use funds appropriated under subsection (a) for the purposes described in subsection (b).

[(d) Of the amounts appropriated under subsection (b), at least 75 percent shall be used for grants under section 152(b) and the remainder shall be used for grants under section 152(c).]

SEC. 154. (a) For the purpose of grants under subsections (a), (d), and (e) of section 152, there are authorized to be appropriated $11,400,000 for fiscal year 1991, $12,390,000, for fiscal year 1992, $13,430,000 for fiscal year 1993 and $14,310,000 for fiscal year 1994. Amounts appropriated under this section for a fiscal year shall remain available for obligation and expenditure until the end of the succeeding fiscal year.

(b) For the purpose of grants under section 152(b) and 152(c), there are authorized to be appropriated $7,000,000 for fiscal year 1991, $8,652,000 for fiscal year 1992, $10,386,000 for fiscal year 1993, and $12,050,000 for fiscal year 1994.

(c) The Secretary may use funds appropriated under subsection (a) for the purposes described in subsection (b).

PART E—PROJECTS OF NATIONAL SIGNIFICANCE

PURPOSE

SEC. 161. The purpose of this part is to provide for grants and contracts for projects of national significance to increase and support the independence, productivity, and integration into the community of persons with developmental disabilities[.] *and to support the development of national and State policy which enhances the independence, productivity, and integration of persons with developmental disabilities through data collection and analysis, technical assistance to program components, technical assistance for the development of information and referral systems, educating policymakers, Federal interagency initiatives, and the enhancement of minority participation in public and private sector initiatives in developmental disabilities.*

GRANT AUTHORITY

SEC. 162. (a) * * *

* * * * * * *

(1) projects of national significance relating to persons with developmental disabilities, including projects to educate policymakers, develop an ongoing data collection system, [determine the feasibility and desirability of developing a nationwide information and referral system] *promote the development of regional and national information and referral networks* and pursue Federal interagency initiatives, and other projects of sufficient size and scope and which hold promise of expanding or otherwise improving opportunities for persons with developmental disabilities (especially those who are multihandicapped or disadvantaged, including minority groups, Native Americans, Native Hawaiians, and other underserved groups); and

[(2) technical assistance and demonstration projects (including research, training, and evaluation in connection with such projects) which hold promise of expanding or otherwise improving the advocacy functions of the State Planning Council, the functions performed by university affiliated programs and satellite centers under part D, and protection and advocacy services relating to the State protection and advocacy system described in section 142.]

(2) technical assistance and demonstration projects (Including research, training, and evaluation in connection with such projects) which expand or improve the functions of the State Planning Council, the functions performed by university affiliated programs and satellite centers under part D, and protection and advocacy system described in section 142.

AUTHORIZATION OF APPROPRIATIONS

[SEC. 163. (a) To carry out this part, there are authorized to be appropriated $3,650,000 for fiscal year 1988, $3,650,000 for fiscal year 1989, and $3,650,000 for fiscal year 1990.

[(b) Of the amounts appropriated under subsection (a) for any fiscal year, $600,000 shall be available for grants and contracts under section 162(a)(1) for not more than three projects to deter-

mine the feasibility and desirability of developing a nationwide information and referral system for persons with developmental disabilities. The Secretary shall award grants and contracts under section 162(a)(1) for such projects within 6 months after the date of enactment of the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987.]

SEC. 163. AUTHORIZATION OF APPROPRIATIONS.

(a) IN GENERAL.—To carry out this part, there are authorized to be appropriated $3,900,000 for fiscal year 1991, $4,095,525 for fiscal year 1992, $4,299,750 for fiscal year 1993, and $4,514,800 for fiscal year 1994.

(b) LIMITATION.—At least 8 percent of the funds appropriated pursuant to the authority of subsection (a) shall be used to carry out the provisions of section 162(a)(2).

* * * * * * *

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